

A State Health Department Approach to Promoting Cancer Genomics Through Surveillance, Education and Policy

July 16, 2012

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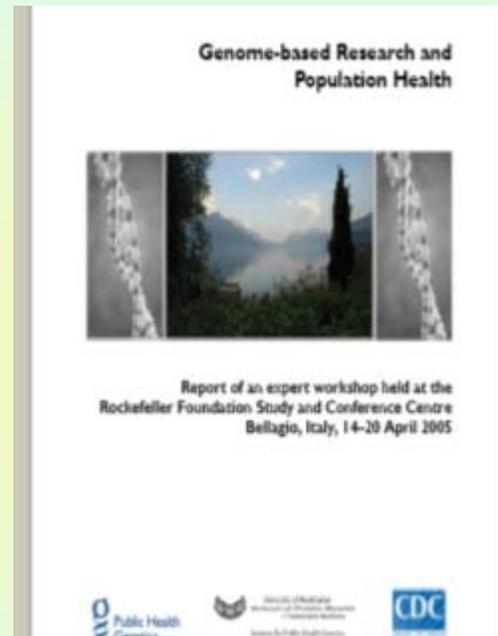
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What is Public Health Genomics? (Bellagio Statement, 2006)

- A multidisciplinary field concerned with the effective and responsible translation of genome-based knowledge and technologies to improve population health



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commentary

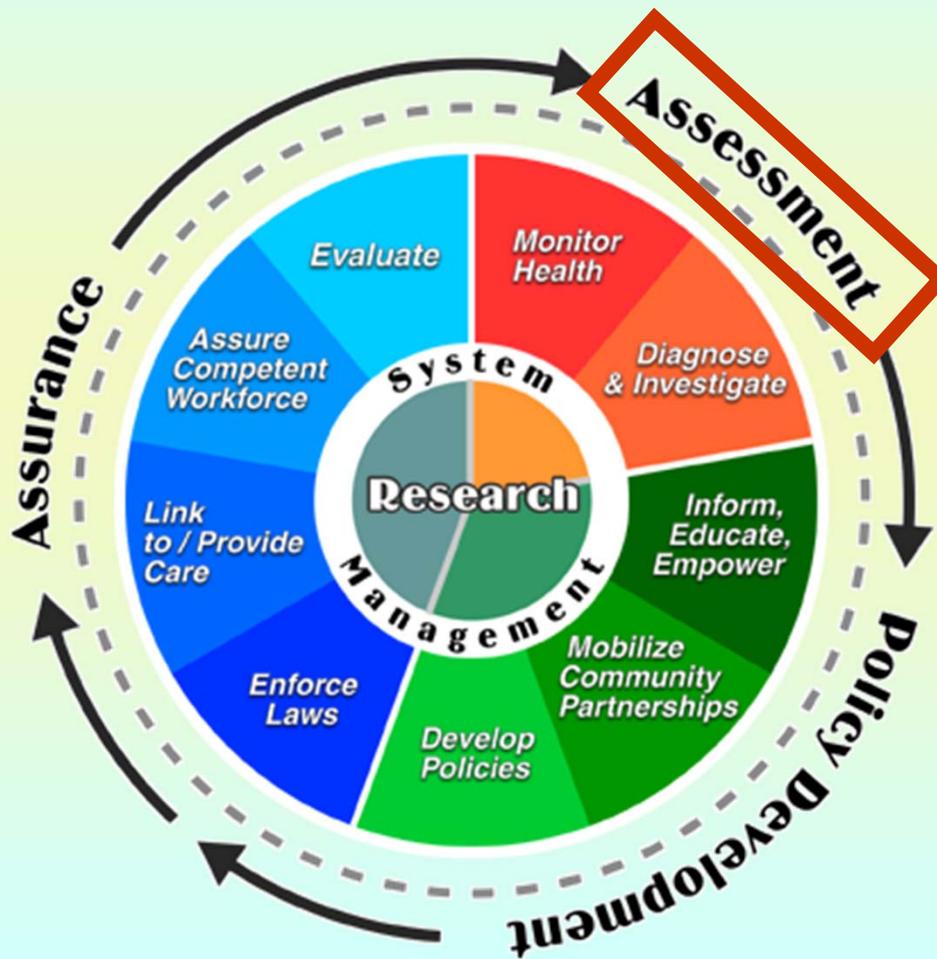
The path from genome-based research to population health: Development of an international public health genomics network

Wylie Burke, MD, PhD¹, Muin J. Khoury, MD, PhD², Alison Stewart, PhD³, and Ronald L. Zimmern, MA, FFPHM⁴ for the Bellagio Group⁵

The health benefits of the Human Genome Project have been widely anticipated. Experts predict a new era of individualized disease prevention based on testing for genetic susceptibilities,¹ and safer, more effective use of drugs based on

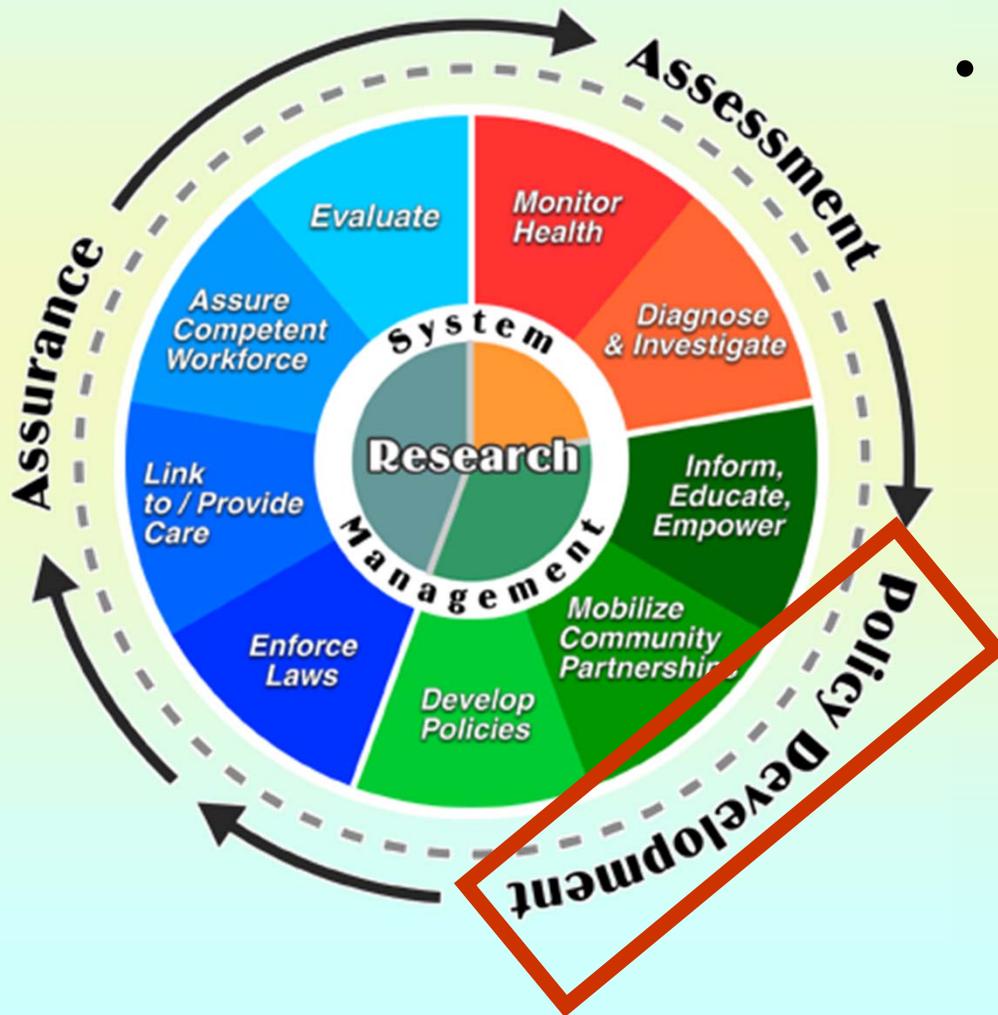
Which vision of the future should the prudent clinician believe: A cornucopia of healthcare innovations based on genomic research, or a stream of genetically-based interventions that fail to deliver value to the public? We argue that both visions are

Three Core Public Health Functions and Ten Essential Services



- **Assessment:** The regular systematic collection, assembly, analysis, and dissemination of information, including genetic epidemiologic information, on the health of the community.

Three Core Public Health Functions and Ten Essential Services



- **Policy Development:** The formulation of standards and guidelines, in collaboration with stakeholders, which promote the appropriate use of genomic information and the effectiveness, accessibility, and quality of genetic tests and services.

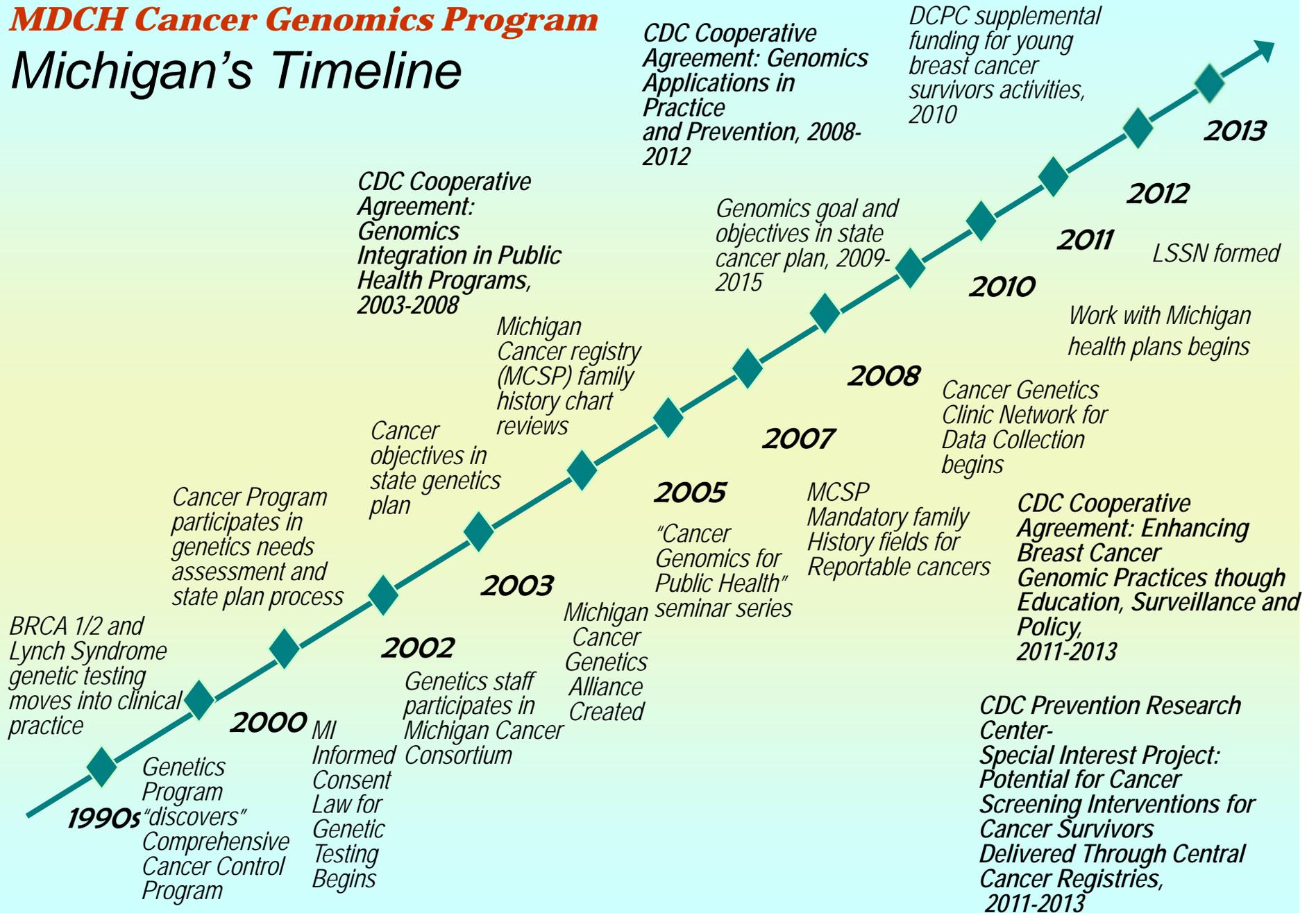
Three Core Public Health Functions and Ten Essential Services



- **Assurance:** That genomic information is used appropriately and that genetic tests and services meet agreed upon goals for effectiveness, accessibility, and quality.

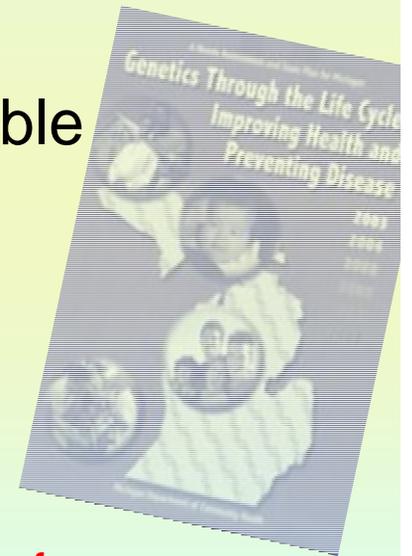
MDCH Cancer Genomics Program

Michigan's Timeline



Cancer Genomics & the State Genetics Plan, 2003-2008*

- Goal #1: Increase genetic literacy in the State of Michigan
 - Expand public and provider knowledge regarding the impact of genetics on health
- Goal #2: Assess the public health impact of heritable conditions and the utilization of genetic services
 - Conduct public health surveillance and research regarding hereditary cancer in Michigan
- Goal #3: Improve access to genetic information, prevention strategies and services
 - Educate health insurance plans and providers about the value of genetic services



* Funding for the Michigan genetics needs assessment and state plan provided by grants from the Maternal and Child Health Bureau (Title V. Social Security Act), Health Resources and Services Administration, Department of Health and Human Services, 2000-2006.

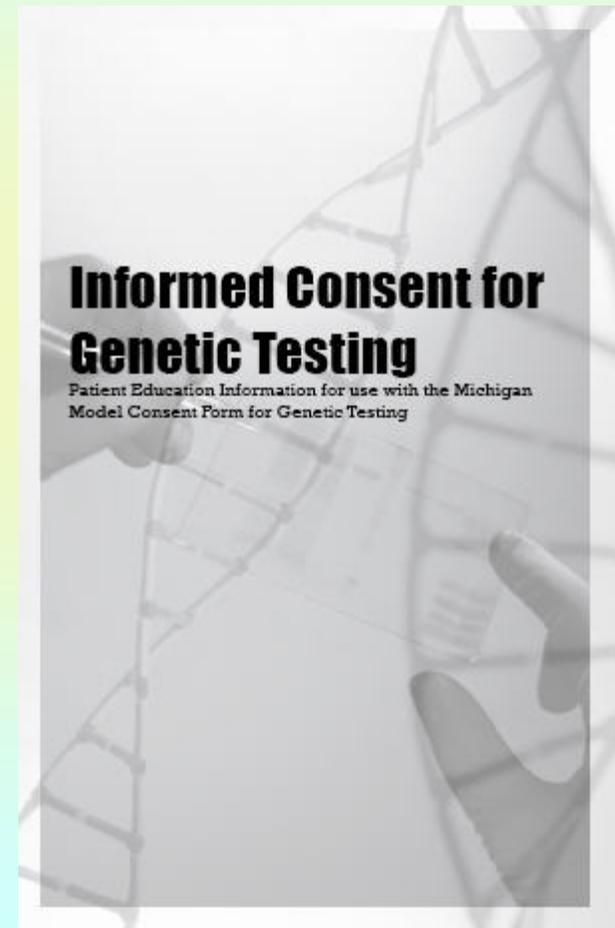
Cancer Genomics & the State Genetics Plan, 2003-2008*

- **Goal #4:** Promote early identification and treatment of individuals with birth defects, heritable disorders or genetic susceptibilities throughout the life cycle
 - Promote use of family history for genetic risk assessment of common chronic conditions
 - Reduce morbidity and mortality related to hereditary cancer by increasing utilization of appropriate cancer risk assessment services
- **Goal #6:** Promote appropriate public health responses to advances in genomics medicine and technology
 - Enhance communications with genetic service providers and promote partnerships with relevant stakeholders
 - Form a new organization of cancer genetics professionals to promote communication, serve as a source of expert information, and participate in the Michigan Cancer Consortium

** Funding for the Michigan genetics needs assessment and state plan provided by grants from the Maternal and Child Health Bureau (Title V. Social Security Act), Health Resources and Services Administration, Department of Health and Human Services, 2000-2006.*

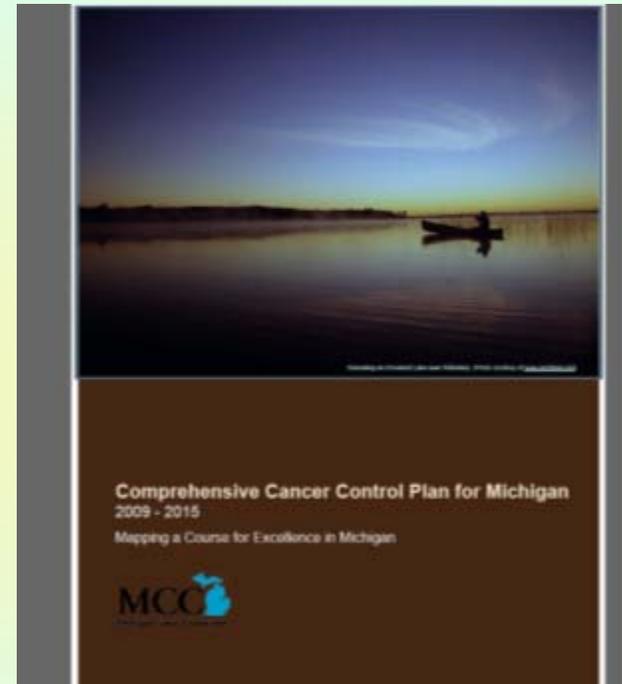
Michigan Informed Consent Law for Genetic Testing, 2000

- ***Michigan law states that a provider shall not order “a presymptomatic or predictive genetic test without first obtaining the written, informed consent”***
- Nature and purpose of the test
- Effectiveness and limitations
- Implications of taking the test, including, but not limited to, the medical risks and benefits.
- The future uses of the sample taken and the information gained from the test.
- The meaning of the test results and how results will be disclosed
- Who will have access to the patient’s sample and result and the right to confidentiality



Comprehensive Cancer Control Plan for Michigan 2009-2015

- **Goal:** Increase availability of cancer-related genetic information to the Michigan public and decrease barriers to risk-appropriate services
 - **Implementation Objective 1:** By 2011, expand public knowledge about the impact of genetics on cancer risk and management (breast, ovarian, and colorectal cancers)
 - **Implementation Objective 2:** By 2015, expand provider knowledge about the impact of genetics
 - **Implementation Objective 3:** By 2015, improve genetic health care financing and access to testing and support services



<http://michigancancer.org/>

Genomics Integration in State Cancer Plans, 2005-2010

- 2005 review¹ of 30 existing comprehensive cancer control plans:
 - 18 plans (60%) with specific terms related to genomics
- 2010 review² of 50 existing comprehensive cancer state plans:
 - 47 plans (94%) with specific terms related to genomics
 - Most common genomics term found ‘family history’ (43/47 plans)
 - Specific genetic tests less commonly mentioned
 - *BRCA* (18/47 plans)
 - Lynch syndrome (6/47 plans)

1. http://www.cdc.gov/pcd/issues/2005/apr/04_0128.htm

2. Presented at National Conference on Public Health Genomics (2010) by J. Laufman, M. Victor, B. Burke, D. Duquette and J. Flome

Genomics Integration in State Cancer Plans, 2005-2010 (continued)

- 32 plans (64%) with at least one genomics goal, strategy or objective
 - Most common goal/theme identified (24/32 plans) related to:
 - Increase access to genetic risk assessment services such as genetic counseling or genetic testing including reimbursement for genetic risk assessment services
 - Second most common goal/theme (18/32 plans) related to:
 - Educating public and providers about family history or developing family history tool
 - Six states had goals, strategies or objectives related to assurance, assessment and policy (Michigan, Minnesota, Mississippi, New Mexico, Oregon, Washington)
 - Michigan, Minnesota and Oregon funded from CDC OPHG, 2003-2008
- Online survey to 47 comprehensive cancer state programs with at least one genomic term, April-May 2011 (response rate 40.4%)
 - Barriers to implementation identified:
 - low priority of genomics; time constraints; lack of sufficient staff/leadership; lack of funding
 - Possible facilitators to implementation of genomics goal, strategy or objective identified:
 - increased funding; stronger partnerships with health insurance companies

- ***“...efforts are needed not only to implement what is known in genomics to improve health but also to reduce potential harm and create the infrastructure needed to derive health benefits in the future.”***

- Khoury M et al. Am J Prev Med 2011; 40(4):486-493

Three-Tier Classification of Recommendations on Genomic Applications

- **Tier 1: Ready for implementation** (per evidence-based recommendation on clinical utility)
 - Encourage use; can save lives
 - Examples: **BRCA, Lynch syndrome**, familial hypercholesterolemia, newborn screening
- **Tier 2: Informed decision making** (adequate information on analytic and clinical validity, promising but not definitive information on clinical utility)
 - Provide information for shared decision making
 - Examples: **Gene expression profiles in breast cancer**, family history assessment in primary care
- **Tier 3: Discourage use** (no or little information on analytic, clinical validity or clinical utility; or evidence of harm)
 - Discourage use; reduce potential harms and save unnecessary healthcare costs
 - Examples: Population screening for hereditary hemochromatosis, personal genomic tests sold directly to consumers

Healthy People 2020 Genomics Objectives

The screenshot displays the HealthyPeople.gov website interface. At the top, there is a search bar and navigation links for Home, About Healthy People, 2020 Topics & Objectives, Implementing Healthy People, Consortium & Partners, and Stay Connected. The main content area is titled "Genomics *New*" and includes tabs for Overview, Objectives, and Interventions & Resources. Two objective entries are visible: G-1 (increase genetic counseling for women with family history of breast/ovarian cancer) and G-2 (increase genetic testing for Lynch syndrome). Each entry has a "View Details" button. Download links for PDFs of all Genomics Objectives are provided. The footer contains various policy and contact links, and a statement that the site is managed by the U.S. Department of Health and Human Services.

HealthyPeople.gov

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Genomics *New*

[Overview](#) [Objectives](#) [Interventions & Resources](#)

[Download all Genomics Objectives](#) [PDF – 10 KB] [Expand All Objectives](#)

G-1 Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling

G-2 (Developmental) increase the proportion of persons with newly diagnosed colorectal cancer who receive genetic testing to identify Lynch syndrome (or familial colorectal cancer syndromes)

[Download all Genomics Objectives](#) [PDF – 10 KB] [Expand All Objectives](#)

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A Federal Government Web site managed by the [U.S. Department of Health and Human Services](#)

2005 U.S. Preventive Services Task Force BRCA Recommendation

Women whose family history is associated with an increased risk for deleterious mutations in BRCA1 or BRCA2 genes should be referred for genetic counseling and evaluation for BRCA 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/uspstf05/brcagen/brcagenrs.htm>

Evaluation of Genomic Applications in Practice and Prevention (EGAPP)

The screenshot shows the EGAPP website interface. At the top left is the EGAPP logo, which includes the text "Evaluation of Genomic Applications in Practice and Prevention (EGAPP)". Below the logo is a navigation menu with the following items: Home, About EGAPP, Working Group, Understanding EGAPP, Topics, Methods, Evidence Reports, Recommendations, Other EGAPP Activities, Resources, and Contact Us. Below the menu is a text box that reads: "The EGAPP Working Group was established in 2005 to support the development of a systematic process to evaluate evidence regarding the validity and utility of rapidly emerging genetic tests for clinical use. Independent, multidisciplinary panel prioritizes and selects tests, reviews CDC commissioned evidence, contextual factors, highlights critical knowledge gaps, and provides guidance on appropriate use in specific clinical contexts." At the bottom of the screenshot are two buttons: "What's New" and "EGAPP Recommendations".

EGAPP RECOMMENDATION STATEMENT

**Recommendations from the EGAPP Working Group:
genetic testing strategies in newly diagnosed individuals
with colorectal cancer aimed at reducing morbidity and
mortality from Lynch syndrome in relatives**

*Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group**

EGAPP RECOMMENDATION STATEMENT

**Recommendations from the EGAPP Working Group:
can tumor gene expression profiling improve outcomes
in patients with breast cancer?**

*Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group**

EGAPP Recommendation on Genetic Testing for Lynch Syndrome

- Sufficient evidence to offer counseling & genetic testing for Lynch syndrome to patients newly diagnosed with colorectal cancer to reduce morbidity & mortality in relatives
- Relatives of patients who test positive for Lynch could be offered counseling, testing &, if positive, increased colonoscopy
- Evidence of benefit to the patient's relatives

Gen Med 2009;11:35-41 & 42-65

CDC Funding Announcement
***Genomics Applications in Practice and Prevention
(GAPP): Translation Programs in Education,
Surveillance, and Policy***

- 3 year cooperative agreement (2008-2011) awarded to four projects
 - Large, well-defined populations in US (greater than 100,000)
- **Goal:** move human genome applications into health practice to maximize health benefits and minimize harm through non-research activities
- Expected measurable outcomes:
 - **Surveillance:** measure use of counseling and testing for BRCA1/2; knowledge of providers or public on use of BRCA1/2 or EGAPP-identified genetic test(s); use of EGAPP genetic test(s); use of family history tools
 - **Provider Education:** increase knowledge of validity, utility, harms and benefits of EGAPP-identified genetic test(s); increase use of family history, counseling and BRCA1/2 tests as recommended by USPSTF
 - **Policy:** increase use of family history, counseling, and BRCA1/2 tests as recommended by USPSTF

MDCH-CDC Cooperative Agreements for Cancer Genomics Surveillance, Education, and Policy

Promoting Cancer Genomics Best Practices through Surveillance, Education, and Policy Change in the State of Michigan (CDC-RFA-GD08-801)

- Awarded from CDC Office of Public Health Genomics, 2008-2011
- Supplemental Funding from CDC Division of Cancer Prevention and Control (DCPC) in 2010/2011
- One-year no-cost extension in 2011/2012

Enhancing Breast Cancer Genomics Best Practices and Policies in the State of Michigan (CDC-RFA-DP11-1114)

- Awarded from CDC DCPC to MDCH, 2011-2014
- Authorized from Affordable Care Act

CDC Cooperative Agreement for Promoting Cancer Genomics Best Practices Through Surveillance, Education, and Policy Change in the State of Michigan, 2008-2011

- Multi-faceted, state-wide comprehensive program
- Translation of evidence-based recommendations for genetic tests into practice
 - USPSTF BRCA recommendations
 - EGAPP recommendations on Lynch syndrome
 - EGAPP recommendation on breast cancer gene expression profiling
- Evaluate effectiveness in changing provider knowledge, test use, insurance coverage

Promoting Cancer Genomics Best Practices through Surveillance, Education and Policy Change in the State of Michigan, 2008-2011

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 2008-2012

- 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

Funding for this project was made possible by Cooperative Agreement #5U38GD000054 from the Centers for Disease Control and Prevention. The contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

Target Population

State of Michigan

◆ **Public**

- ~ 10 million residents
- ~ 6.9 million under age 50

◆ **Health systems and providers**

- ~200 facilities reporting to the Michigan Cancer Surveillance Program (excludes labs, dermatology and dental offices)
- ~64,000 new reportable cancer cases per year

◆ **Health insurance plans**

- 24 health plans



Policy Objectives

- Understand current status of Michigan health insurance policies for BRCA1/2 counseling and testing with respect to USPSTF guidelines and related clinical services for BRCA1/2 mutation carriers
- Understand current status of Michigan health insurance policies for Lynch syndrome genetic testing with respect to EGAPP recommendations
 - No known health plans with written policies for Lynch syndrome testing in alignment with EGAPP recommendations
- Increase the number of health plans that have policies consistent with USPSTF guidelines

Resources

- USPSTF BRCA Recommendations
- EGAPP Lynch Syndrome Recommendations
- Health Plan Champion
- Michigan Cancer Consortium
- Michigan Cancer Genetics Alliance
- MDCH Genomics Program

Activities

- ✓ Review Michigan health plan policies for consistency with USPSTF BRCA recommendation, coverage for clinical services for BRCA positive members, and consistency with EGAPP Lynch recommendation
- ✓ Disseminate USPSTF guidelines and need for related clinical services for BRCA 1/2 mutation carriers to health plans through multiple venues
- ✓ Track BRCA counseling and testing at 10 clinical cancer genetics clinics for members with and without health plan policies consistent with USPSTF
- ✓ Recognize health plans consistent with USPSTF
- ✓ Provide technical assistance to health plans
- ✓ Conduct a workshop for health plans and cancer genomics experts

Policy

Performance Measure

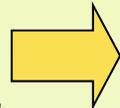
★ Use of family history, genetic counseling and BRCA 1/2 testing (as recommended by USPSTF) and related clinical services increases from baseline

Promote Use of Identified Health Insurance Policy Model

Surveillance of Health Plan BRCA 1/2 Policies

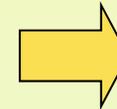
Methods:

- Contracted with “health plan champion” and Michigan Association of Health Plans (MAHP)
- Identified total of 24 Michigan health plans
- Using multiple search types (i.e. websites, key administration contacts, list serves, newsletters, conferences) request and/or identify policies



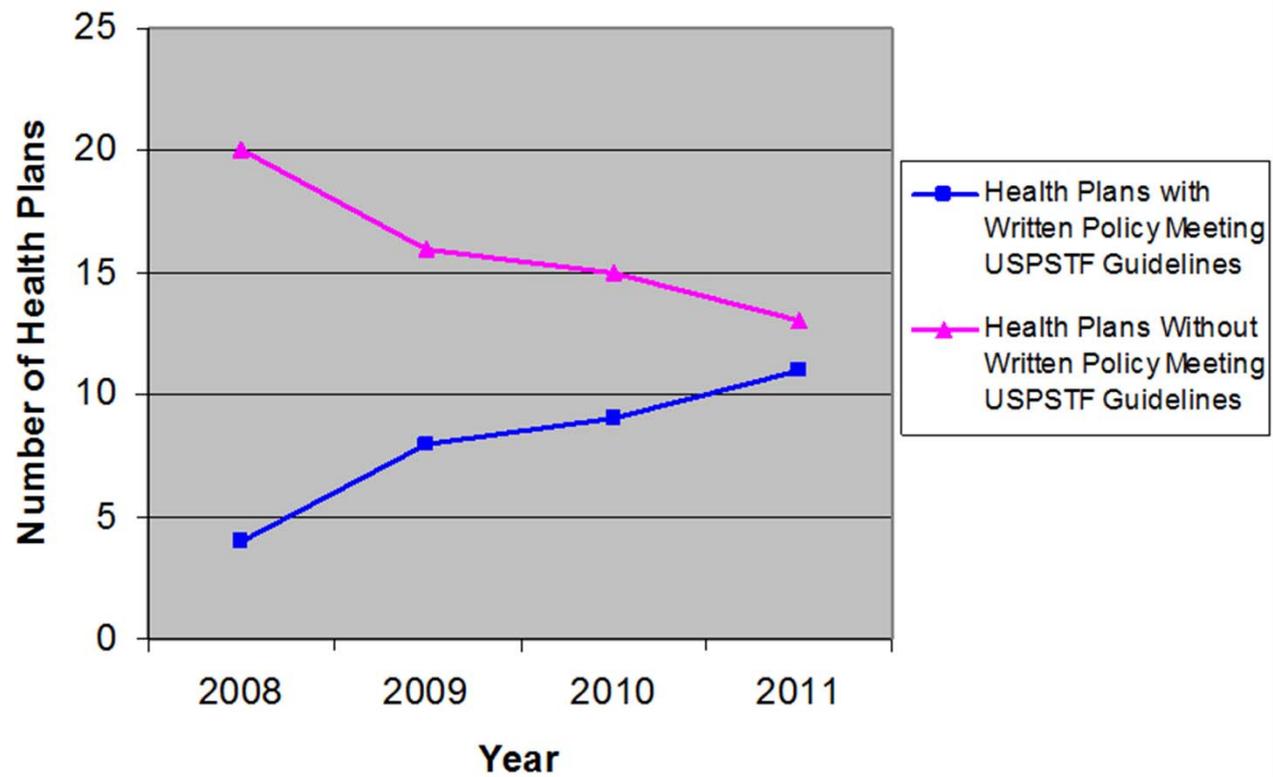
Conduct ongoing surveillance to determine:

1. Does the health plan have a written BRCA counseling and testing policy?
2. If written policy, does it include coverage for female members with a significant family history of breast and/or ovarian cancer without a personal history (aligned with USPSTF)?
3. Does the policy ‘require’ or ‘strongly recommend’ counseling by a qualified health care professional or genetic counselor prior to BRCA testing?



Consider aligned with USPSTF if all three criteria are fulfilled

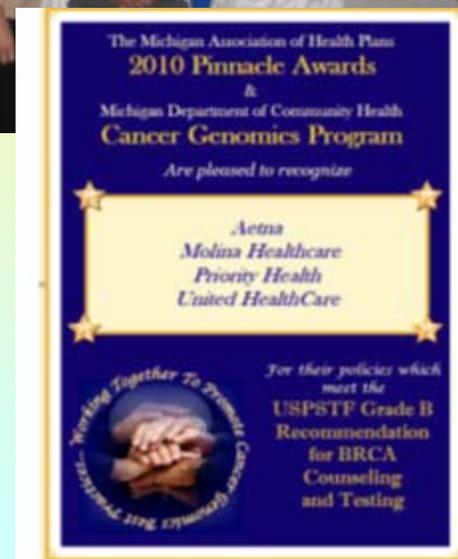
Health Plans in Michigan with a Written BRCA Policy Meeting USPSTF Guidelines



Health Plan	<i>BRCA1/2</i> written policy (Y/N)	Consistent with USPSTF	Distribution (%) of Visits Covered at Cancer Genetic Counseling Sites (n=9,851)*	Number of Michigan Health Plan Members*
12 Health Plans	Y	Y	8,036 (83.8%)	~7.5 million
9 Health Plans	N	N	166 (1.6%)	~1 million
1 Health Plan	Y	N (no genetic counseling recommendation)	4 (0.0%)	187,000
Medicaid	Y	N (only personal history coverage)	279 (2.8%)	500,000+
Medicare	Y	N (only personal history coverage)	1,257 (12.8%)	~1.5 million

Honoring Health Plans Aligned with USPSTF Grade B Recommendation

- Michigan Association of Health Plans (MAHP) Summer Conference held in 2010-2012
- Announcement regarding regulations requiring new health insurance plans to cover preventive care for USPSTF Grade A & B Recommendations on July 14, 2010
- Pinnacle Awards to honor health plans aligned with USPSTF Grade B BRCA Recommendation in 2010-2012
- Pinnacle Award for best BRCA policy awarded to Priority Health in 2011
- CME Best Practices event to educate health plan directors in 2010-2012
- MAHP *Insight* Magazine
- MAHP and MDCH Press Releases
- Michigan Cancer Consortium Update Newsletters
- Michigan Cancer Genetics Alliance meetings and listserv announcements



Promoting USPSTF Grade B BRCA Recommendation to Health Plans

- Educate health plans about USPSTF Grade B BRCA Recommendation and Best Practices
 - Health plan conferences
 - CME events
 - Displays
 - Provider tools
 - Articles in newsletters

Michigan Association of Health Plans

JOIN THE MAHP FOUNDATION FOR THE ANNUAL BEST PRACTICES FORUM

WEDNESDAY, DECEMBER 8, 2010
8:00 A.M. TO 2:00 P.M.
THE ENGLISH INN

MAKE YOUR CALENDARS AND PLAN TO JOIN THE PINNACLE AWARD RECIPIENTS FOR THE ANNUAL BEST PRACTICES FORUM. THIS YEAR'S PROGRAM WILL BE AT THE CONFERENCE CENTER OF THE ENGLISH INN IN EATON RAPIDS - A WONDERFUL SETTING IN ALL SEASONS OF THE YEAR. HIGHLIGHTS OF THE FORUM WILL INCLUDE:

- * PRESENTATION OF PINNACLE AWARD WINNING PROGRAMS AND OPPORTUNITIES FOR DISCUSSION WITH THE PEOPLE RESPONSIBLE FOR DESIGNING AND IMPLEMENTING THE PROGRAMS
- * IN COLLABORATION WITH THE MDCH CANCER GENOMICS PRO SPECIAL PRESENTATION ABOUT GENETIC COUNSELING AND SCREENING FOR CANCER, AND DISCUSSION WITH HEALTH PLANS THAT HAVE IMPLEMENTED THE US PREVENTIVE SERVICES GUIDELINES
- * OPPORTUNITY TO MEET WITH THE PINNACLE AWARD GOLD AND SILVER SPONSORS AND LEARN MORE ABOUT THEIR PRODUCTS AND SERVICES
- * NETWORKING WITH COLLEAGUES.

WATCH FOR DETAILED INFORMATION IN THE WEEKS AHEAD.

insights

And Ahead
Budget and
Reform:
Opinions and Comments

for Doctors,
Health Plans

Cancer Genetics Best Practices
...join today to protect ours

Michigan Department of Community Health
Cancer Genetics Program

USPSTF Grade B Recommendation

Informed Consent for Genetic Testing...

It's the law in Michigan!

Notification to Health Plans Not Aligned with USPSTF

- MDCH staff provided individualized packets to Michigan health plans at key events
 - Discuss in person with key health plan administrators
 - Emphasize USPSTF Grade B Recommendation
 - Provide summary of project and partnership with CDC and MAHP
 - Highlight three criteria required to receive honors
 - Report individualized information for each health plan regarding their assessment
 - Encourage to contact MDCH or MAHP for technical assistance

ment of Community Health Cancer Genomics Program, in partnership with the Centers for Disease Control and Prevention and the Michigan Association of Health Plans, is seeking health plans to share evidence-based cancer genomics best practices. We would like to thank you for joining this effort. By joining this effort, your health plan will be honored at an upcoming MAHP event.

We encourage your health plan to develop a written policy aligned with the United States Preventive Services Task Force (USPSTF) Grade B Recommendation that includes BRCA1/2 genetic testing for women with a significant family history. *Based on our knowledge, your health plan does not currently have a written policy for BRCA1/2 counseling and testing.*

The Michigan Department of Community Health in partnership with the Michigan Association of Health Plans like to honor those Michigan health insurers who meet three

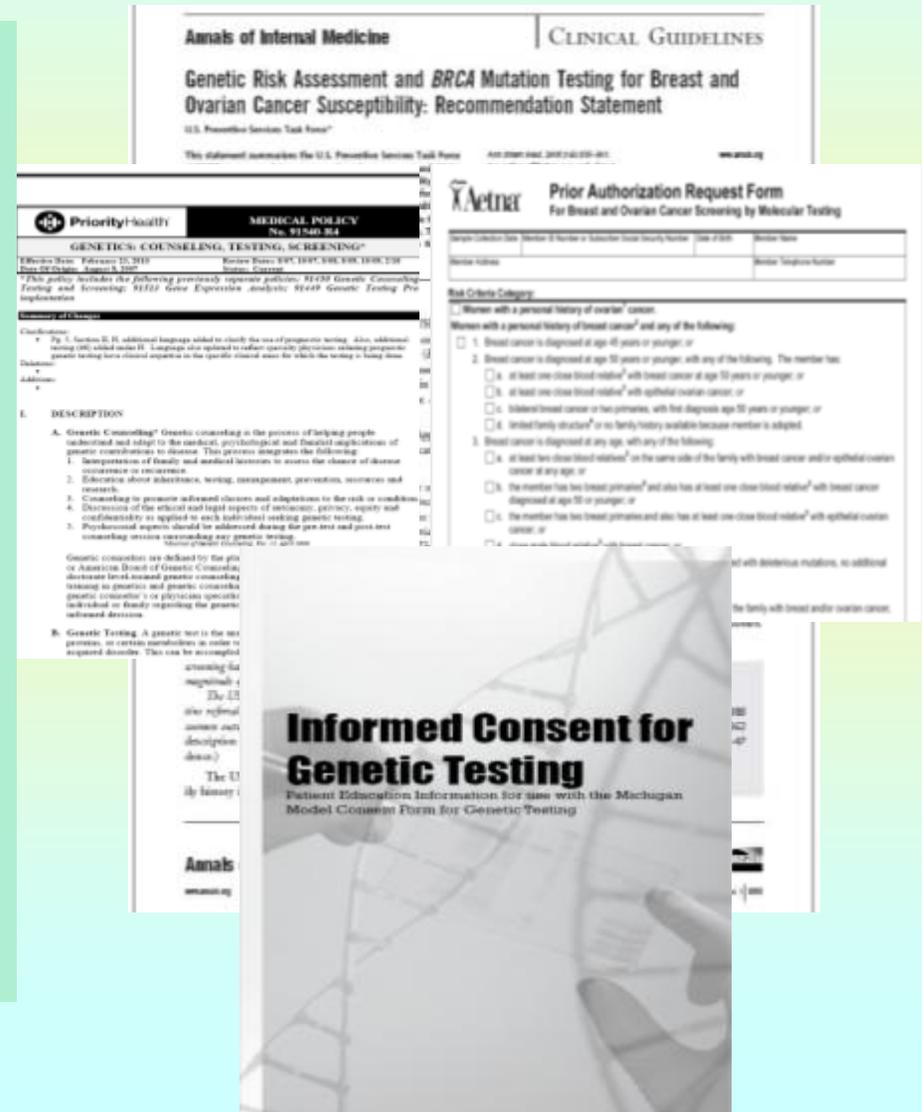
criteria for BRCA 1/2 counseling and testing:
1. A written policy that includes family history criteria for referral to cancer genetic testing aligned with the USPSTF Recommendations
2. A written policy that requires or strongly recommends genetic counseling and genetic testing. This recommendation is also aligned with Michigan's informed consent prior to predictive genetic testing.

Health plans such as Molina Healthcare and UnitedHealthcare are current MAHP members and are considered to have a model policy for BRCA1/2 genetic testing. *For health plans considering establishing a model policy for BRCA1/2 counseling and testing, if you would like further assistance or to learn more about this effort, please contact me at Duquette@mdch.state.mi.us*

Educational Materials for Health Plans

Packet of educational materials includes:

- 2005 USPSTF BRCA Recommendation
- Michigan Informed Consent Law for Pre-symptomatic and Predictive Genetic testing
- Cancer Family History Guide©
- Directory of Michigan Cancer Genetic Counseling Services
- Model BRCA Policies with permission from:
 - Aetna
 - Priority Health
 - UnitedHealthcare



Additional Activities with Michigan Association of Health Plans (MAHP)

- Brief survey to identify barriers and facilitators to BRCA policies at MAHP Annual Conference in July 2011
 - Top 2 barriers
 - inefficient access to cancer genetic experts
 - lack of coding transparency
 - Top 2 facilitators
 - frequent requests for written policy by providers
 - cancer genetic expertise among health plan staff
- *BRCA* educational workshop to key health plan administrators at MAHP CME Best Practices annually since December 2010
 - Pre-survey
 - 41% of attendees aware of USPSTF BRCA recommendation
 - Post-survey and 6 month follow-up
 - ***100% of attendees aware of USPSTF BRCA recommendation***

Summary

- Understand current status of Michigan health insurance policies for BRCA1/2 testing with respect to USPSTF guidelines
 - 15 out of 24 health plans with written policies for BRCA coverage as of 2012
 - 12 in alignment with USPSTF recommendations as of 2012
- Increase the number of health plans that have policies consistent with USPSTF guidelines
 - Increased the number of health plans that have policies consistent with USPSTF recommendations from 4 to 12 out of 24 Michigan plans as of 2012
- CDC Division of Cancer Prevention & Control used process as a model to investigate BRCA health plan policies in most states in 2011
- Georgia, Michigan and Oregon received CDC cooperative agreements from 2011-2013; foci on health plans and policy
- Ohio Cancer Genetics Network currently replicating surveillance and education with their health plans

Examples of 2012 Health Plan Policy Enhancements

- Promote USPSTF and NCCN guidelines
- New** 'BRCA Policy Dashboard' for each health plan
- New** BRCA Genetic Counseling & Testing report for each health plan
- New** education resource packet contains:
 - Same resources as previous educational packet **plus**
 - NCCN guidelines for referral and testing for those with personal and/or family history **plus**
 - NCCN guidelines for management for women with known deleterious mutation **plus**
 - Model policies from Cigna and BCBSM of above

Michigan Department of Community Health
MDCH
 201 Townsend Dr. P.O. Box 30195 Lansing, MI 48909 1-800-452-1247 (x3-8247)

Sample Health Plan

Member Report on BRCA Genetic Counseling & Testing

MDCH Cancer Genetics Database (October 2007-March 2011)

Hereditary Breast and Ovarian Cancer (HBOC) syndrome, caused by a mutation in the BRCA1 or BRCA2 gene, accounts for approximately 5-10% of all breast cancer diagnoses and is associated with increased risk for breast and ovarian cancer. Displayed in the table below are the numbers of patients covered by your health plan who were seen by a board-certified genetic counseling physician from October 2007 to March 2011 for assessment of HBOC and possible BRCA genetic testing. Data on over 5,800 patients includes those with a personal history of cancer and those with a significant family history of cancer as determined by the USPSTF Grade B recommendation statement. In addition, we have outlined the total number of SAMPLE HEALTH PLAN patients who received BRCA testing during this timeframe and the total number of patients not tested reporting "inadequate insurance coverage" as the primary reason not to test.

For questions regarding this report, please contact the MDCH Cancer Genetics Team at 1-866-852-1247 or email genetics@michigan.gov.

	Patients Accessing Genetic Counseling for BRCA	
	Health Plan Number (%)	Michigan Clinical Network Total Number (%)
Patients counseled	888	888
With personal history of breast/ovarian cancer	888 (74)	888 (74)
USPSTF family history (no personal history)	888 (26)	888 (26)
Patients tested after counseling	888	888
With personal history of breast/ovarian cancer	888 (74)	888 (74)
USPSTF family history (no personal history)	888 (26)	888 (26)
Patients not testing due to inadequate insurance	888	888

These data include genetic counseling visits from October 5, 2007 - March 31, 2011 as reported to MDCH through a statewide network of board-certified genetic professionals. Special thanks to the following institutions where de-identified patient information was included in this analysis: Beaumont Health System Cancer Genetics Program, Henry Ford Health System, Ingham/PLAC, Karmanos Cancer Institute Genetics Service, Michigan State University Division of Clinical Genetics, Oakland HealthCare System's Genetic Risk Assessment for Cancer Clinic, Providence Hospital, Medical Genetics, Spectrum Health Cancer Genetics Program, University of Michigan Cancer Genetics Clinic, and University of Michigan Breast and Ovarian Cancer Risk and Evaluation Program. Without the commitment and effort of these institutions, this work would not be possible.

* These counseling services pertain to data on patients residing in Michigan only.

BREAST CANCER GENOMICS BEST PRACTICES

for Michigan Health Plan Partners



Hereditary Breast and Ovarian Cancer Syndrome (HBOC)

MICHIGAN DEPARTMENT OF COMMUNITY HEALTH
 CANCER GENOMICS PROGRAM

2012

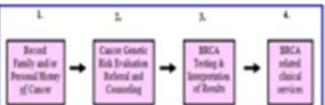
Michigan Department of Community Health
MDCH
 Michigan
 My Health, My Choice

SAMPLE HEALTH PLAN BRCA Policy Dashboard



This score card was created for Sample Plan as an update on progress toward developing written policies related to all four areas of cancer genetic services (Figure 1). For more information on policy development or for technical assistance from MDCH Cancer Genetics Program staff call 1-866-852-1247 or email genetics@michigan.gov. If this scorecard is not accurate, please contact us immediately. We would greatly appreciate up-to-date information from all health plans in Michigan.

Figure 1. Spectrum of Cancer Genetic Services



 = policy is consistent with project standards
 = policy is not consistent with project standards
 = policy is unavailable/unknown if consistent with project standards

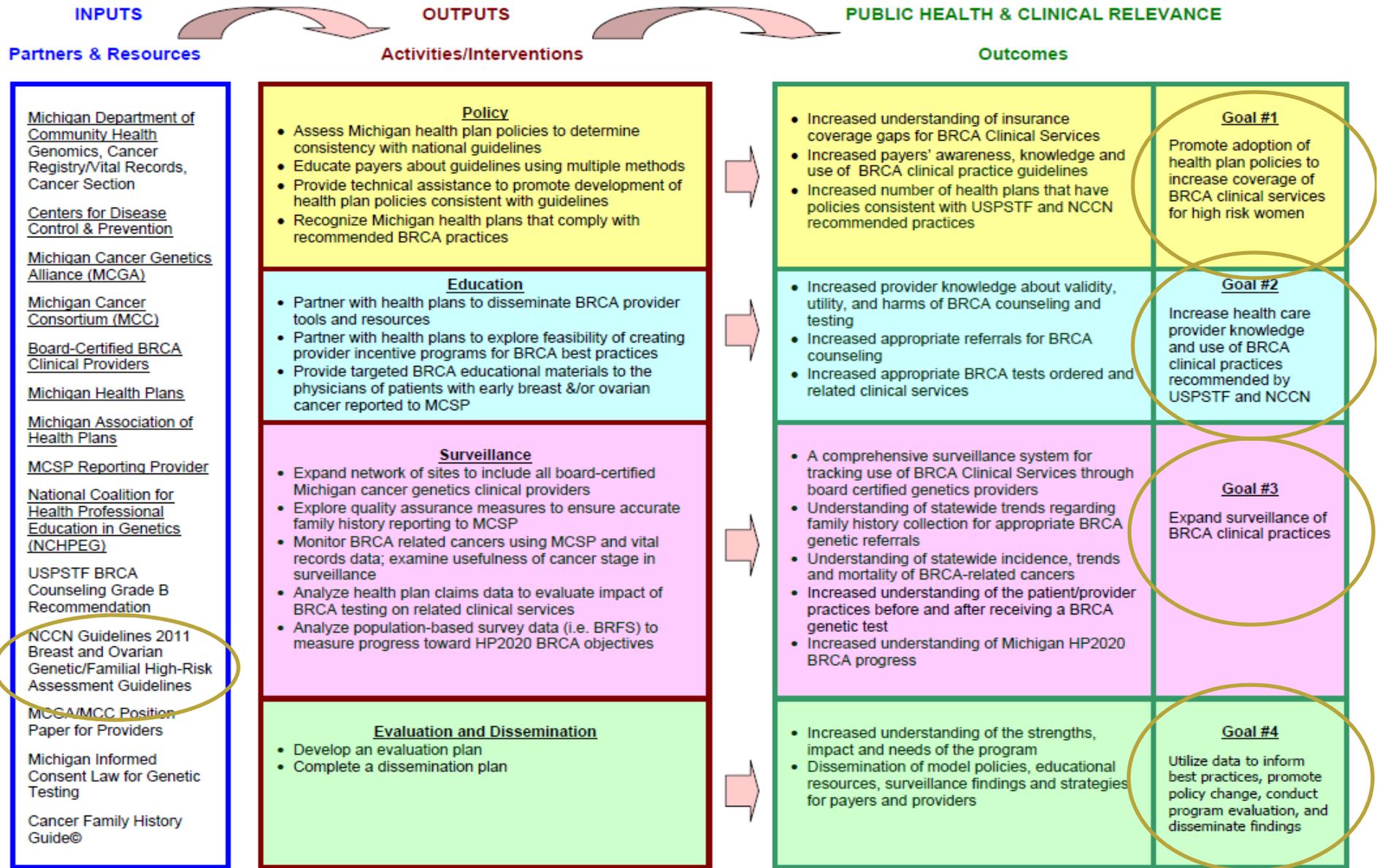
Your health plan has written policies related to BRCA that...

1. include coverage for the following individuals:	
<ul style="list-style-type: none"> Adults with a personal history of breast and/or ovarian cancer.¹ Adults with a family history of breast and/or ovarian cancer.^{1,2} 	 
2. require or strongly recommend genetic counseling prior to BRCA genetic testing.	
3. encourage providers to obtain written informed consent (as is required by Michigan law) prior to ordering BRCA genetic testing.	
4. cover BRCA-related clinical services for positive patients (policies would contain coverage information for the following services) ³	
<ul style="list-style-type: none"> Mammography MRI of the Breast Prophylactic Mastectomy Prophylactic Oophorectomy Breast Reconstruction and Prostheses Genetic Testing for Susceptibility to Breast and Ovarian Cancer Genetic Counseling 	      

1. National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology "Genetics/Familial Risk Assessment: Breast and Ovarian" version 1.2012, accessed July 2012 from www.nccn.org. & 1.1.1. Preventive Services: Risk Factor: Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement. Ann Intern Med 2005; 143: 355-361.

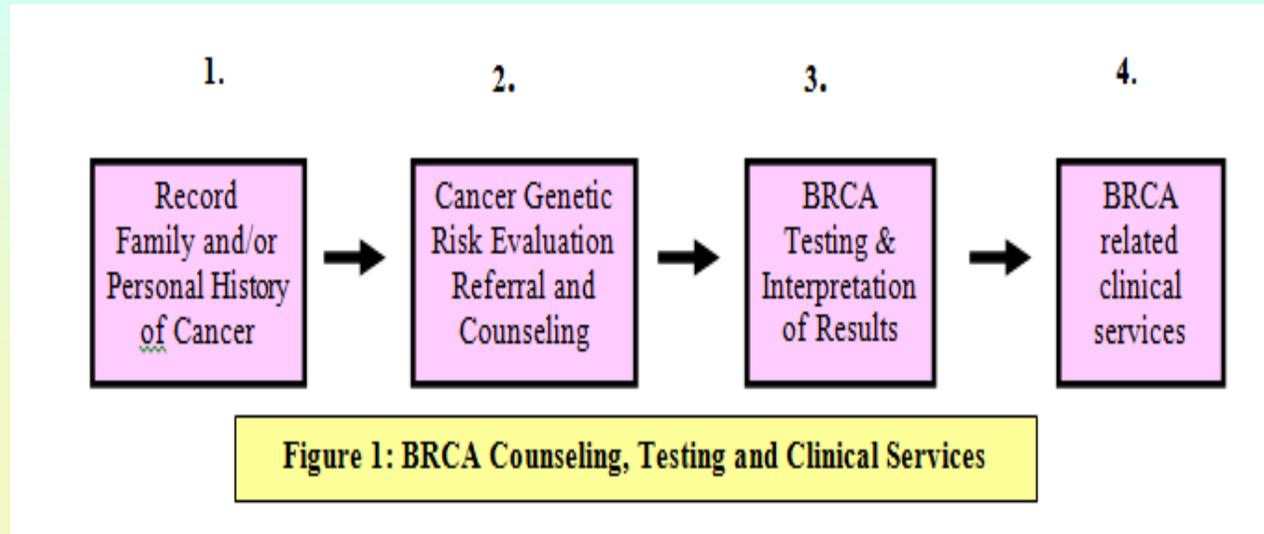


Enhancing Breast Cancer Genomics Best Practices and Policies in the State of Michigan



Ultimate Impact: A reduction in breast cancer deaths at a young age and ovarian cancer deaths in Michigan

Ensure Appropriate Translation of “BRCA Clinical Services”



- 1. Documentation of key cancer family history and personal history elements to conduct risk assessment***
- 2. Referrals to genetic counseling services of patients at high risk for deleterious BRCA mutations based on personal and/or family history of cancer***
- 3. Appropriate BRCA testing with prior written informed consent explaining risks, benefits and limitations of BRCA testing and appropriate interpretation of test results***
- 4. Provision of related clinical services/interventions for patients with a known deleterious BRCA mutation.***

A reduction in breast cancer deaths at a young age and ovarian cancer deaths in Michigan

**Health Plan Champion;
Michigan Association
of Health Plans (MAHP);
Blue Cross Blue Shield
of Michigan**

**Michigan Cancer Consortium;
FORCE**

Policy

**Michigan Cancer
Genetics Alliance**

**CDC Division of Cancer Prevention and Control
CDC Office of Public Health Genomics**

**MDCH
Genomics Program**

**15 Clinical
Cancer Genetics
Sites**

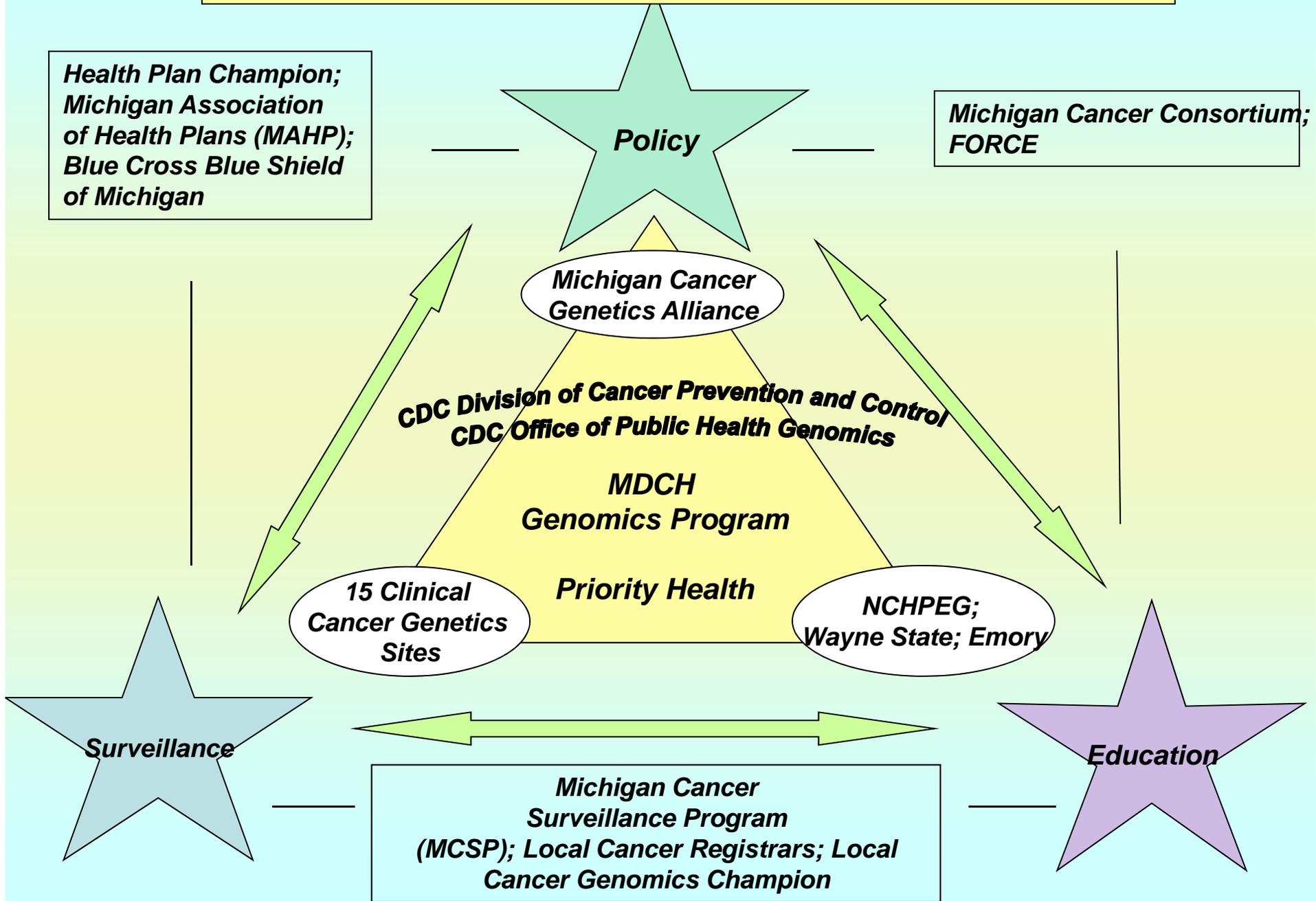
Priority Health

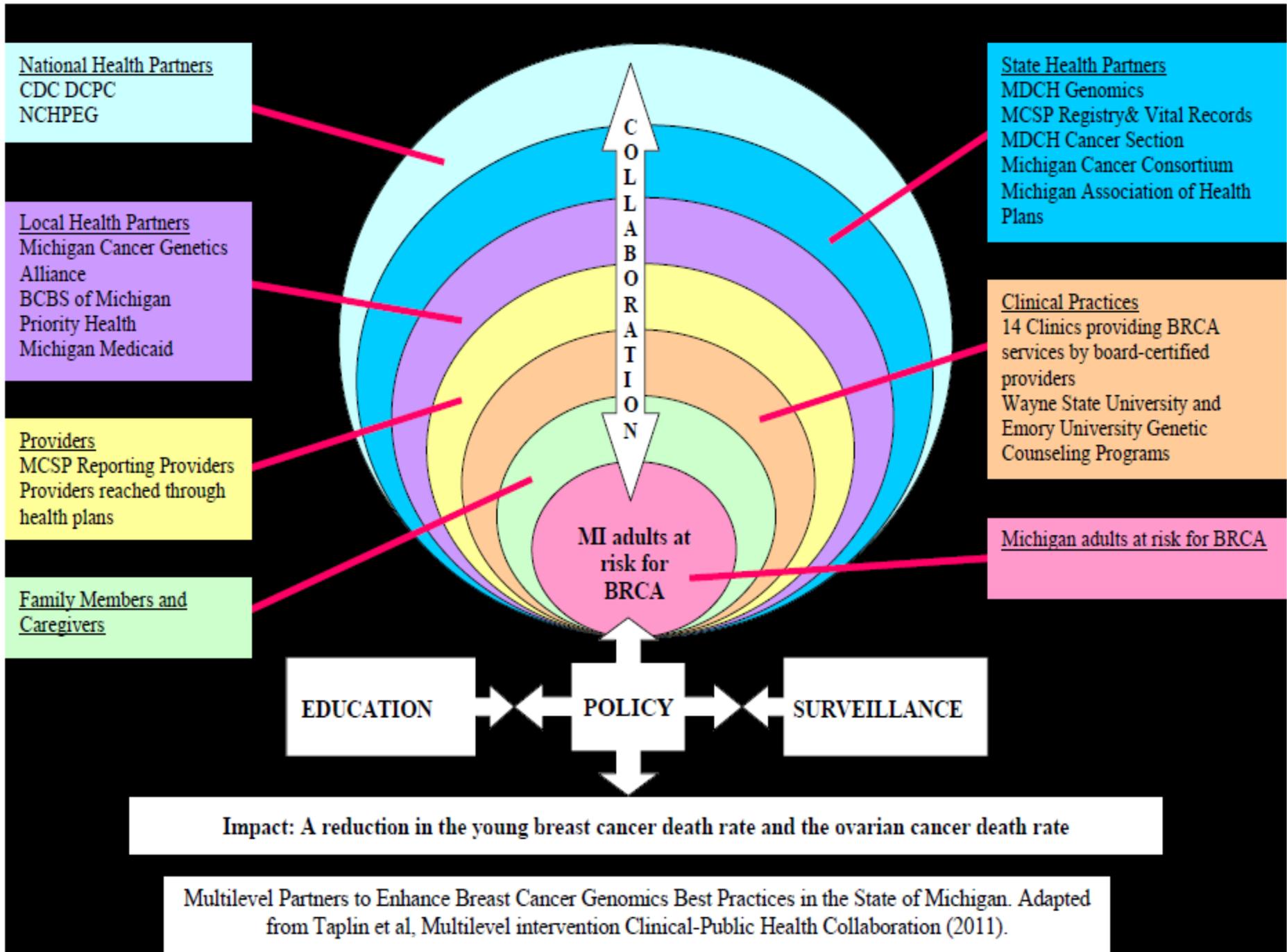
**NCHPEG;
Wayne State; Emory**

Surveillance

Education

**Michigan Cancer
Surveillance Program
(MCSP); Local Cancer Registrars; Local
Cancer Genomics Champion**





Surveillance Objectives

- To examine the epidemiology of multiple primaries, early onset breast, male breast, ovarian and Lynch syndrome cancers
- To evaluate the use of genetic counseling and tests:
 - Who is accessing genetic counseling? and testing?
 - What providers are referring for genetic counseling?
 - Is referral for counseling appropriate using USPSTF family history guidelines?
 - For patients having BRCA testing, what are their test results?
 - Do health plan policies that are consistent with USPSTF guidelines influence visits?
 - Is the number of women with a family history of breast and/or ovarian cancer receiving genetic counseling increasing?
- To assess barriers/facilitators to cancer survivors knowledge and attitudes about family health history, genetic counseling and testing
- To provide data that will reinforce educational messages to health care providers

Michigan Cancer Surveillance Program (MCSP)

- Statewide reporting since 1985
- Registry established by law (Act 82 of 1984)
- Includes in situ or invasive malignancies other than basal or squamous nongenital skin; benign brain and CNS tumors since 2004
- ~64,000 new reportable cases per year
- 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



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)

Multiple Primaries Methods

- 1990-2007 cancer registry data, with at least one diagnosis in 2006 or 2007
- 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
- Oregon has also examined cancer registry data using similar methods

Facility-specific Profiles



Jennifer M. Granholm, Governor
Janet Olszewski, Director

A Cancer Genetics Profile: Prepared for **Sample Hospital**



Focusing on Your Patients' Hereditary Cancer Risk

March 1, 2010



201 Townsend St. P.O. Box 30195 Lansing, MI 48909 1-866-852-1247 (toll-free)

Sample Facility Specific Cancer Genetics Data Report (2006-2007) on Hereditary Breast and Ovarian Cancer Syndrome (HBOC) 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 HBOC syndrome 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. HBOC 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. Age 18-49 at diagnosis	Sample Facility 2006 - 2007	Michigan 2006 - 2007
Breast (female)	199	3,025
Endometrial	30	459

Table 1. Number of early onset female breast and endometrial diagnoses within your health system and within Michigan.

Table 2. All ages	Sample Facility 2006 - 2007	Michigan 2006 - 2007
Colorectal	476	10,340
Ovarian*	127	1,544
Breast (male)	12	147

Table 2. Number of colorectal, ovarian* cancer and male breast diagnoses within your health system and within Michigan.

Table 3. All ages	Sample Facility 2006 - 2007	Michigan 2006 - 2007
Multiple primary cancer diagnoses	106	1,985

Table 3. Number of people with multiple cancer diagnoses between 1990 to 2007 with a cancer diagnosis in 2006-2007 including: breast-breast, breast-ovarian*, ovarian*-ovarian*, colorectal-colorectal, colorectal-endometrial, colorectal-ovarian*, endometrial-endometrial, ovarian*-endometrial.

* 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
 - USPSTF *BRCA*
 - EGAPP Lynch syndrome
- 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
- Assist facility to meet ACOS Cancer Program Patient Care Improvement Standards 6.2 or 8.2
- ***Since November 2011 also highlight New Commission Cancer Genetic Counseling Standards***



JENNIFER M. GARRINHOUM
SOLICITOR GENERAL

State of Michigan
DEPARTMENT OF COMMUNITY HEALTH
LANSING

JANET OLSZEWSKI
DIRECTOR

May 2010

Dear Healthcare Partner:

The Michigan Department of Community Health (MDCH) is pleased to provide this Cancer Genetic Profile. The profile highlights the number of cancer patients at your facility who may be at risk for Hereditary Breast and Ovarian Cancer (HBOC) syndrome or Lynch Syndrome (also called Hereditary Non-Polyposis Colorectal Cancer Syndrome or HNPCC). Patients who have early onset cancer, multiple primary diagnoses of cancer, rare cancer, or a significant family history are at increased risk for the above conditions. These patients should be offered genetic counseling to discuss the risks, benefits, and limitations of genetic testing and to evaluate the need for increased cancer surveillance. Identifying those at risk for hereditary cancer benefits patients and family members who may be unaware of the familial risk.

As you may know, healthcare facilities in Michigan must report cancer diagnoses to the Michigan Cancer Surveillance Program (MCSF). We analyzed case reports received in 2005-07 to create a summary specifically for your facility. In addition, your facility's cancer registrar will be sent the names of patients who might be at increased risk for hereditary cancer so you may determine whether appropriate genetic services were offered. Included in this profile are:

- Facility Report with the number of cancer patients at your facility who may be at risk for hereditary disease
- Clinical recommendations for patients with a family history of breast and/or ovarian cancer
- Clinical guidelines for the evaluation of Lynch syndrome in colorectal cancer patients
- Genetic and Family History resources and resource CD with additional printable patient and provider education resources.
- The Michigan Informed Consent Law Booklet
- Contact information for the Cancer Genomics Educator at the Michigan Department of Community Health

The resources and services provided in this profile may also be used to meet the American College of Surgeons (ACS) Cancer Program Patient Care Improvement Standards. Standards 6.2 and 8.2 focus specifically on early prevention or detection programs and improving direct patient care respectively. MDCH is sharing your facility's data with you in order to promote evidence-based practices for the appropriate use of genetic services and tests. Your individual report will not be shared with any parties outside your health system and is for internal use only.

The MDCH cancer genomics educator, Ms. Jenna McLosky, MS, CGC, is available to discuss this report in greater detail. If you would like to order copies of the enclosed resources or schedule an on-site training about hereditary cancer, please contact Ms. McLosky at 517-335-8828 or mdchgen@mdch.state.mi.us.

Thank you for helping to promote cancer genomics best practices within the state of Michigan.

Sincerely,

Gregory S. Holzman, MD, MPH
Chief Medical Executive

Who received the report?

- 107 NPCR facilities in 2010-2011
- 38 SEER facilities in 2011
- For each facility, multiple key administrators sent report including:
 - Cancer Registrar
 - President and CEO
 - Medical/Clinical Affairs
 - Medical Director
 - Quality Assurance/Risk Management
 - Patient Care
 - Legal Affairs
 - Nursing
 - Oncology
 - OB/GYN

Free Provider In-Services Offered

**Dr. Decision-Maker
and the Family of Secrets**

A choose your own adventure
approach to hereditary cancer risk
and management

Jenna McLosky, MS, CGC
Cancer Genomics Education Coordinator
Michigan Department of Community Health



Chapter 6: The Case of the Unexpected Syndrome

Your patient is a 30-year-old, African American female seen in clinic for her annual check up. She is currently healthy and reports no change in her medical history. Today, her breast exam is negative.

Upon reviewing her intake, you discover that her mother had breast cancer at age 60 and her sister recently had breast cancer at age 40. You ask if there are any other cancers in the family, and she reports "not that I can think of."



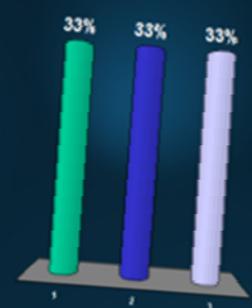
**Dr. Decision-Maker
and the Family of Secrets**

Goals of this experience:

- Increase provider knowledge of hereditary cancer risk, family history "red flags" and genetic testing options for hereditary cancer syndromes.
- Increase provider confidence in obtaining and evaluating cancer family histories and providing appropriate medical follow up for hereditary risks.
- Increase awareness of current evidence-based guidelines on genetic testing for hereditary cancer syndromes and gene expression profiling tests.

How do you proceed?

1. Her risk for hereditary cancer seems increased. You refer her for a mammogram.
2. Refer her to a qualified healthcare professional to discuss her family history and possible genetic testing.
3. This case really does seem clear cut. After thorough discussion and informed consent, you draw the patient's blood for genetic testing (BRCA1/2).



Option	Percentage
1	33%
2	33%
3	33%

- ✓ Real-life clinical scenarios
- ✓ Critical decision-making skills
- ✓ Uses interactive audience response system
- ✓ Promotes USPSTF guidelines for Hereditary Breast and Ovarian Cancer syndrome
- ✓ Promotes EGAPP Recommendation for Lynch syndrome

2012 Bidirectional Process Updates

- Seven Michigan facilities requested names from cases reported to provide appropriate follow-up
- MDCH piloting process of reporting ~200 cases diagnosed in 2008-2009 from 4-5 NPCR Michigan facilities affiliated with newly established cancer genetics clinics and providing materials directly to physician
- Connecticut successfully replicated process in 2012
 - Received HP2020 funds to implement similar bidirectional process with dissemination of educational materials and provide cancer genomic in-services
 - Utilized select board-certified genetic counselors to provide in-services
 - Greater success than Michigan in percentage of in-services provided

Network of Michigan Clinical Cancer Genetics Clinics

**Collected all BRCA counseling cases from October 2007-
March 2011 seen by a Michigan
board certified/eligible
genetics professional**

**Currently collecting data on
April 2011-October 2013 with
new online database**

**New online database also
identifies if NCCN counseling
and/or testing criteria met**

**Utilizing data in health plan
policy work in 2012-2013**

The image displays a screenshot of a clinical data entry system with several overlapping windows. The top window shows patient information fields: Find Patient (2), Add Patient, Patient Code, Gender, Birth Year, Zip Code, Race, Ashkenazi Jewish, Location, Race 2, Known Familial Mutation, Referring Physician Type, Other Race, Num of 3rd Deg., and USPSTF (No). Below this is a 'Visits' tab with fields for Date, Visit Type, Insurance, and Other Insurance, along with checkboxes for 'No Change In Personal History' and 'No Change In Family History'. A second window shows a table of test results:

Test Date	Test Type	Other Type	Result	Result Date
6/11/2020	Ashkenazi		Negative	6/20/2020
6/20/2020	Comprehensive		Negative	6/30/2020
6/30/2020	Other	HNPCC	Positive	7/15/2020

A third window shows an 'Assessment' table:

Assessment Date	Assessment Type	Assessment Result
6/11/2020	BRCAPro risk	6
6/11/2020		

A fourth window shows a 'Date DX tracked' table:

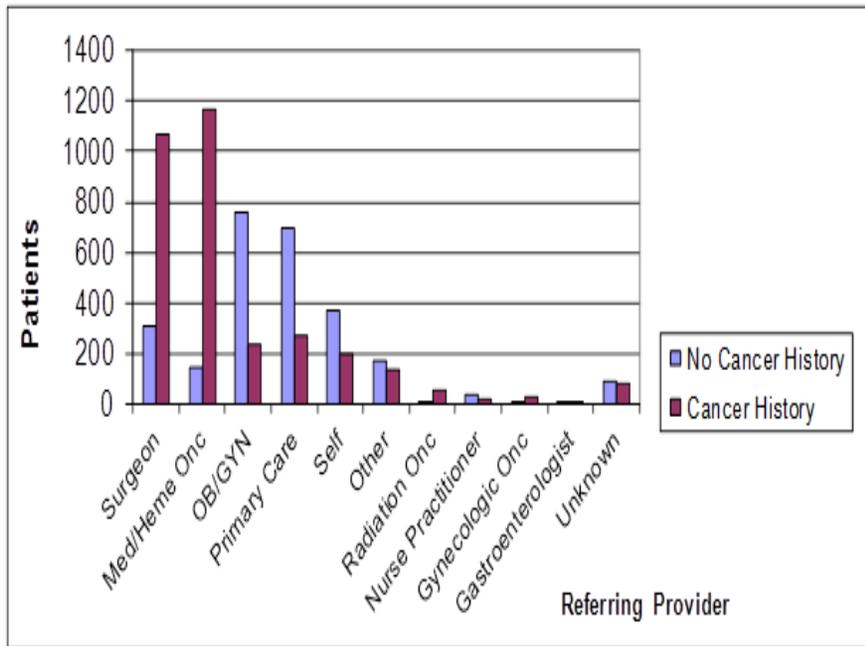
Date DX tracked	Cancer Type	Age At DX
6/11/2020	Breast	22
6/11/2020	Ovarian	27
6/11/2020		

The bottom window shows 'Relative's History' for a 'mother' relationship:

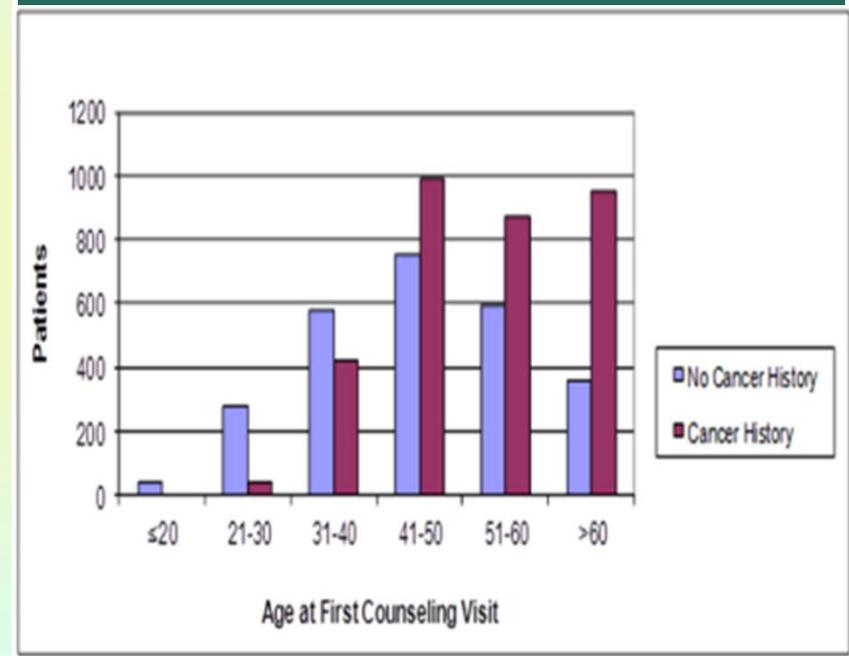
Date DX tracked	Cancer Type	Age At DX
6/11/2020	Colorectal	
6/11/2020	Breast	
6/11/2020	Other	55

Indications for Referral: Personal Cancer History versus Family History only

Referring provider of patients receiving BRCA counseling

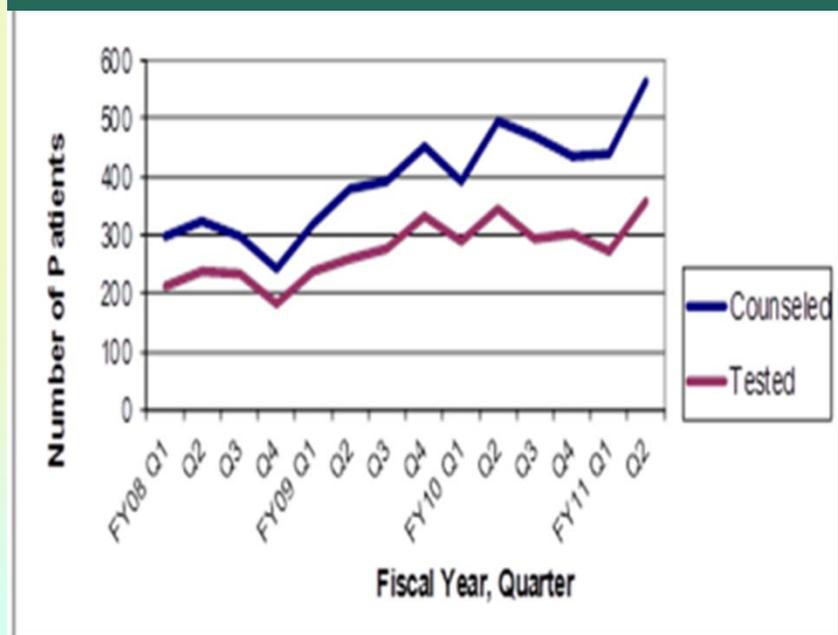


Age at first visit in those with and without a personal history of breast and/or ovarian cancer

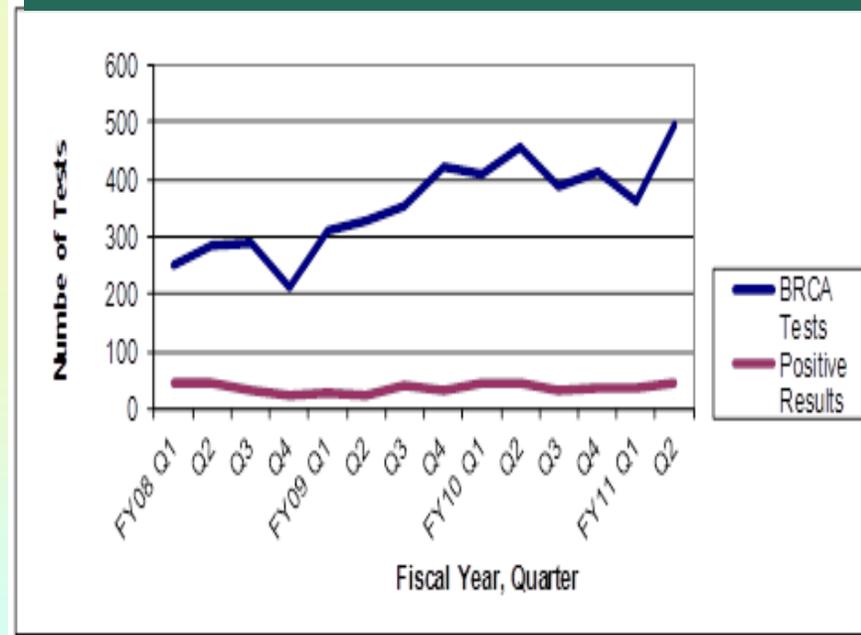


Michigan *BRCA* Counseling, Testing and Known Deleterious Mutation Trends, October 2007-March 2011

Number of BRCA counseling visits and tests per fiscal year quarter, October 2007 through March 2011



Number of BRCA tests and known deleterious mutations per fiscal year quarter, October 2007 through March 2011



BRCA Testing Results by Personal History of Cancer, USPSTF Family History Criteria, and Known Familial Mutation

	Personal Cancer History			No Personal History		Known Familial Mutation
	Ovarian cancer	Breast cancer at ≤ 50 years	Breast cancer at > 50 years	Met USPSTF criteria	Did not meet USPSTF criteria	
Negative	153 (73.6)	1,352 (86.8)	676 (90.1)	432 (90.8)	301 (92.9)	345 (52.8)
Positive	44 (21.2)	135 (8.7)	29 (3.9)	23 (4.8)	8 (2.5)	298 (45.6)
Variant	11 (5.3)	71 (4.6)	45 (6.0)	21 (4.4)	15 (4.6)	10 (1.5)
Total	208	1,558	750	476	324	653

Reasons for declining BRCA genetic testing after receiving genetic counseling	
	Patients
	Number (%)
Not the best test candidate	477 (29.2)
Not clinically indicated	436 (26.7)
Inadequate insurance coverage	243 (14.9)
Other	116 (7.1)
Discuss options with relatives	80 (4.9)
Not a good time	71 (4.4)
Reassured by risk assessment	50 (3.1)
Does not meet Medicare criteria	45 (2.8)
Does not want to know	45 (2.8)
Test co-pay too costly	30 (1.8)
Patient sees no benefit	20 (1.2)
Arrange life/disability insurance	19 (1.2)
Total	1,632

913 patients found to be inappropriate for testing at time of counseling
 (potential cost savings of Over \$3 million)



Interesting Trend:

- In Oct 2007-2008 and Oct 2008-2009, 16.7% of patients who received genetic counseling did not proceed with BRCA testing due to inadequate insurance coverage
- In Oct 2010-2011 (MDCH provider and policy work began in 2010), number dropped to 10.7%
- In Oct 2010-March 2011, number dropped again to 9.7%

Characteristics of patients who had and did not have *BRCA* genetic testing after counseling

	Tested	Did Not Test	P-value
	Number (%)	(%)	
Gender			
Female	3,808 (94.6)	1,655 (96.2)	< 0.01
Male	219 (5.5)	65 (3.8)	
Race			< 0.01*
White	3,333 (82.9)	1,277 (74.2)	
Black	244 (6.1)	183 (10.6)	
Multi-racial	243 (6.0)	153 (8.9)	
Asian / Pacific Islander	76 (1.9)	31 (1.8)	
Arabic	63 (1.6)	36 (2.1)	
Hispanic	33 (0.8)	23 (1.3)	
Native American	2 (0.1)	6 (0.4)	
Other	10 (0.3)	1 (0.1)	
Unknown	17 (0.4)	11 (0.6)	
Ashkenazi Jewish Heritage			< 0.01
No	3,524 (87.6)	1,653 (96.0)	
Yes	498 (12.4)	69 (4.0)	
Known Familial Mutation			< 0.01
No	3,386 (84.2)	1,670 (97.0)	
Yes	636 (15.8)	52 (3.0)	
Family History Defined by USPSTF			0.04
No	2,303 (57.3)	1,035 (60.1)	
Yes	1,719 (42.7)	687 (39.9)	
Personal Cancer History			<0.01
No	1,396 (34.7)	1,132 (65.7)	
Yes	2,626 (65.3)	590 (34.3)	

Surveillance Data Reinforces Key Messages to Referring Providers:

- Test Affected First
- Remember to ask about Ashkenazi Jewish ancestry
- Document prior *BRCA* testing results in family if possible
- Males are important too
- Consider racial/ethnic/cultural differences when counseling
- Personal history of ovarian cancer is especially important

Young Breast Cancer Survivors (YBCS) Mail Survey

- 500 YBCS (diagnosed between 18-49 years of age in 2006-2007) identified through MCSP
- 12 page mail survey sent (up to three attempts)
 - to assess barriers and facilitators to YBCS knowledge, attitudes and use of family history, genetic counseling and testing in regards to *BRCA1/2*
- YBCS who completed survey received gift certificate
- Notified reporting cancer registrars and physician on record for each YBCS prior to sending survey

Michigan Department of Community Health
MDCH
Risk Factors. Resources. The Health Difference.

ID#: _____

**Michigan Department of Community Health
Breast Cancer Survivor Survey**

When you return a completed survey and this consent page with signature, we will send you a \$10 gift card to thank you for your time and answers!! (limit one card)

Informed Consent

This study "Assessment of Utilization of Genetic Services by Early-Onset Breast Cancer Survivors" is being carried out by the Michigan Department of Community Health (MDCH) within the State of Michigan. The purpose of this project is to understand the facilitators and barriers to accessing cancer genetic services within Michigan. Your answers are very important and will help us learn about patient access to clinical cancer genetic services.

Michigan hospitals and doctors are required by law to report all cancer diagnoses to the Michigan Cancer Surveillance Program (MCSP) registry in order to track the number of Michigan residents affected by cancer each year. Your personal information about your diagnosis is housed in a locked database and is kept confidential and private.

You were chosen from the MCSP registry to participate in this study because you had breast cancer before 50 years of age. If you choose to complete the survey you will answer questions in this survey that are related to personal and family history of cancer, if you have received genetics services, if you have had genetic testing and what made it easy or hard for you to get these services. The survey will take approximately 15 to 20 minutes to complete.

If you agree to participate, the MDCH Genomics Program will be given basic information about your cancer diagnosis from the cancer registry, such as the type of cancer you had, your age when you were diagnosed, your age now, etc. However, no identifiable information will be shared such as your name or exact birth date.

This survey may increase anxiety or raise questions for you and your family. It may also increase your knowledge about genetic services and policies. If you would like to talk with someone about cancer risk during or after this survey, certified genetic counselors are on staff at MDCH to assist you.

The MCSP registry staff mailed you this survey on behalf of the MDCH Genomics Program. Your personal and identifiable information has not been shared with anyone outside of the MCSP registry. Your survey responses will be kept separate from your identity. MDCH staff will not be able to link your identity with your survey answers. Any personally identifying information will be protected to the extent allowable by law.

<p>If you have any questions regarding the study, please contact: Deb Duquette Phone: 517-335-8286 Toll Free: 1-866-852-1247 Email: genetics@mdch.michigan.gov</p>	<p>If you have any questions about the rights of human research subjects, please contact: Phone: 517-241-1928 Email: MDCH-IRB@michigan.gov</p>
--	---

Taking this survey is voluntary. Choosing not to fill out the survey will not harm you in any way. You may skip any questions you do not want to answer. All information from this survey will be kept strictly confidential.

Your signature below indicates your voluntary agreement to participate in this study. When you return your completed survey with your signed consent form, this consent page (page 1) will be torn away from your answers and a copy will be sent to you with a \$10 gift card.

Signature

Date

Please return the consent form and survey to the address below or use the enclosed postage paid envelope:
Survivors Survey
Michigan Cancer Surveillance Program
P.O. Box 30691
Lansing, Michigan 48913

IRB approval date: 1/21/2010 IRB expiration date: 1/21/2011

YBCS Survey Results

Table 8. Facilitators of <i>BRCA</i> Genetic Counseling & Risk Assessment in YBCS	
	n=122 (42.2%)
REASONS FOR GOING	
Benefit my family's future	105 (86.1%)
Wanted to know my future risk of cancer	62 (50.8%)
My doctor recommended that I go	50 (41.0%)
May alter my cancer treatment	48 (39.3%)
Going seemed very important	41 (33.6%)
Family members wanted me to go	21 (17.2%)
Already knew of a familial mutation	3 (2.5%)
FACTORS THAT MADE IT EASIER TO GO	
My medical insurance covered the visit	83 (68.0%)
Clinic was close to home	49 (40.2%)
Have available transportation	49 (40.2%)
Clinic hours were flexible and fit my schedule	30 (24.6%)
Have available childcare	11 (9.0%)
I was able to obtain these services by phone	2 (1.6%)

- 289 YBCS responded (59.2%)
- 122 YBCS (42.2%) reported having received cancer genetic services
 - Most frequent reason to benefit family's future
 - 121 reported *BRCA* testing
 - 13.2% reported known deleterious mutation
 - 4.1% reported variant of uncertain clinical significance
 - 74.4% reported no *BRCA* mutation found
 - 116 (95.9%) shared results with relatives

YBCS Survey Results (continued)

- 158 (54.7%) YBCS did not receive genetic services
 - Top three reasons:
 - No one recommended (58.2%)
 - Health insurance coverage issues (23.4%)
 - Did not know existed (10.8%)

Table 9. Barriers to Receiving Genetic Services Among YBCS	
	n=158 (54.7%)
No one ever recommended it	92 (58.2%)
Medical insurance coverage issues	37 (23.4%)
Did not know they existed	17 (10.8%)
Worried a genetic test could be used against me	15 (9.5%)
Too nervous	6 (3.8%)
A doctor told me not to go	5 (3.2%)
Lack of transportation	4 (2.5%)
Other life arise that are more important	4 (2.5%)
Too busy	3 (1.9%)
Disability makes it difficult to carry out daily activities	2 (1.3%)
Family members wouldn't want me to go	2 (1.3%)

YBCS Survey Expanded in 2011-2013: Recruiting Young Breast Cancer Survivors and High-Risk Relatives to a Randomized Trial using a State Cancer Registry



Aim 1: Identify and survey 3,000 YBCS (diagnosed at 20-45 y.o.) to determine breast cancer surveillance utilization and perceived barriers and facilitators to surveillance

Aim 2: Identify and survey up to 2 unaffected female relatives (first and/or second degree) per YBCS to determine breast cancer screening utilization and perceived barriers and facilitators to screening

Aim 3: Test the efficacy of two versions (targeted vs. enhanced tailored) of an evidence-based intervention among YBCS and their female relatives to increase breast cancer surveillance/screening utilization

Using Michigan BRFSS to Measure HP2020 BRCA Objective

- 2008 Michigan Behavioral Risk Factor Survey (MiBRFS)
 - 8.7% of Michigan adult women had significant family history of breast and/or ovarian cancer
 - **Only 18% (11.8-26.4) of these women had received genetic counseling due to this family history**
- 2009 MiBRFS
 - 7.9% of Michigan adult women had significant family history of breast and/or ovarian cancer
 - **35.7% (24.8-48.2) of these women had received genetic counseling due to this family history**
 - Please be cautious in evaluating this trend since small numbers (n=136) and confidence intervals overlap slightly
- 2011 MiBRFS results pending
- 2012 MiBRFS currently being conducted

Partners, Partners, Partners...!

“...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”



Acknowledgements



Clinical Sites

Beaumont Hospital
Henry Ford Health System
Karmanos Cancer Institute
Oakwood Hospital
University of Michigan, Breast Cancer Risk Assessment Clinic
University of Michigan, Cancer Genetics Clinic
Informed Medical Decisions, Inc
Michigan State University
St. John-Providence West
Spectrum Health
St. Mary's Hospital
St. Joseph's Hospital
Marquette General Hospital
Mid Michigan Cancer Center
West Michigan Cancer Center

Michigan Association of Health Plans (MAHP)

Priority Health

Blue Cross/Blue Shield of Michigan

Office of Public Health Genomics, CDC

Division of Cancer Prevention and Control, CDC

Michigan Department of Community Health (MDCH) Genomics Program

Michigan Cancer Surveillance Program

MDCH Cancer Prevention and Control Section

Wayne State University

Emory University

National Coalition for Health Professional Education in Genetics (NCHPEG)

New 2012 Important Cancer Genomics Resources

- Cancer Resource Foundation, Inc. provides Genetic Testing Co-Pay Assistance Program
 - 2012 pilot in Massachusetts, Michigan, Ohio, Indiana and Illinois
 - Since January 2012, Michigan has had 47 health care providers enroll
 - Co-pay assistance provided to 15 Michigan residents for 18 cancer genetic tests
 - Now being introduced to all states
 - Provides co-pay assistance for genetic testing for hereditary cancer syndromes (up to approximately \$520)
 - Eligible patients must have insurance; meet specific income criteria (<250% Federal Poverty Threshold); meet NCCN guidelines for testing

The screenshot shows the Cancer Source website interface. At the top, there is a blue navigation bar with the "cancer source" logo and links for "GET HELP", "LEARN", and "DONATE". Below the navigation bar, a tagline reads "One source for free, customized cancer resources. by Cancer Resource Foundation, Inc." The main content area is titled "GET HELP" and features a sidebar with "OUR PROGRAMS" including Genetic Testing Programs, Post-Mastectomy Products and Services, and Get Help with Costs. The main content area is titled "Genetic Testing Programs" and includes a photograph of a family. To the right of the photo are two orange buttons: "Apply Now >" and "Am I Eligible?". Below the photo, there is text explaining eligibility for free genetic testing and a link to "Program Details...". At the bottom, there is a "LEARN" section with a link to "Read more about genetic testing...".

Lynch Syndrome Screening Network (LSSN)



<http://www.lynchscreening.net>

- Created in September 2011 with one-time funding from CDC OPHG
- Founding Board of Directors from MDCH, Emory University, Huntsman Cancer Institute, The Ohio State University
- Institutional membership with 92 institution applications to date
 - Up to 2 individuals/institution
- 52 institutions currently providing routine tumor screening for Lynch syndrome on all or subset of cancers
- 10 additional institutions planning to implement within 6-12 months

LSSN Vision and Mission

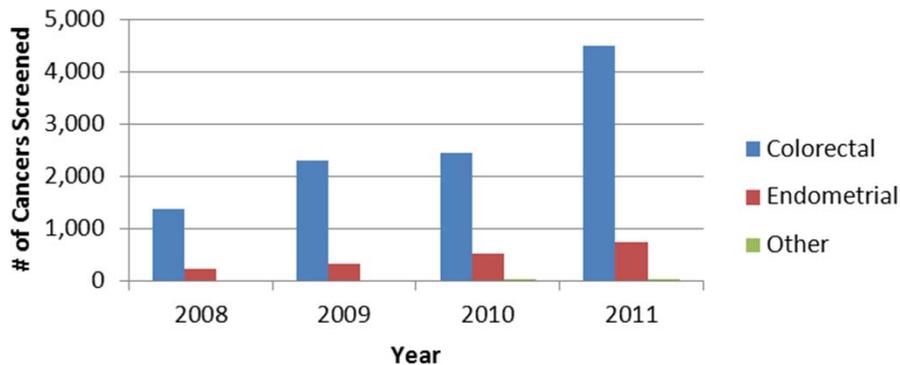
- LSSN Vision:
 - to reduce the cancer burden associated with Lynch syndrome.
- LSSN Mission:
 - to promote universal Lynch syndrome screening on all newly diagnosed colorectal and endometrial cancers; to facilitate the ability of institutions to implement appropriate screening by sharing resources, protocols and data through network collaboration; and to investigate universal screening for other Lynch syndrome related malignancies

LSSN Activities

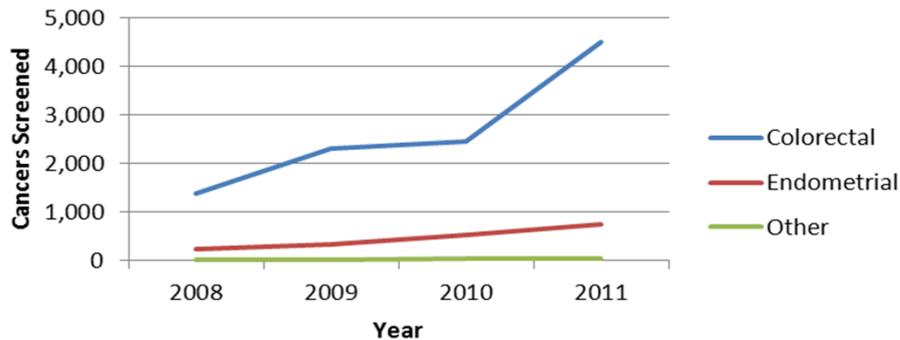
- Two in-person meetings held; next in-person meeting on Oct 27, 2012 in Boston
- Creation of active listserv
- Creation of website and educational materials
- Creation of database
- Multiple research proposals in development
- Creation of CDC OPHG Blog in March 2012
- Creation of bylaws
- Creation of membership application
- Four active workgroups (data, research, education, membership) meet regularly by conference call

LSSN Membership Application Data

Number of cancers screened for Lynch syndrome at time of pathological diagnosis, per year



Number of cancers screened for Lynch syndrome at time of pathological diagnosis, per year



- Impact of 2009 EGAPP Lynch syndrome recommendation
 - 58/62 institutions reported that EGAPP impacted their institutions
 - 24/62 institutions reported EGAPP supported/justified existing screening protocols
 - 23/62 institutions reported EGAPP provided basis for initiating Lynch screening protocol at their institution

Thank you!

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