

Partnering with a State Cancer Registry to Identify Patients at Risk for Inherited Cancers

November 16, 2013

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Michigan Department of
Community Health

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

July 2006 • Vol. 8 • No. 7

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, FPPHM⁴ 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

Genome-based Research and
Population Health



Report of an expert workshop held at the
Rockefeller Foundation Study and Conference Centre
Bellagio, Italy, 14–20 April 2005



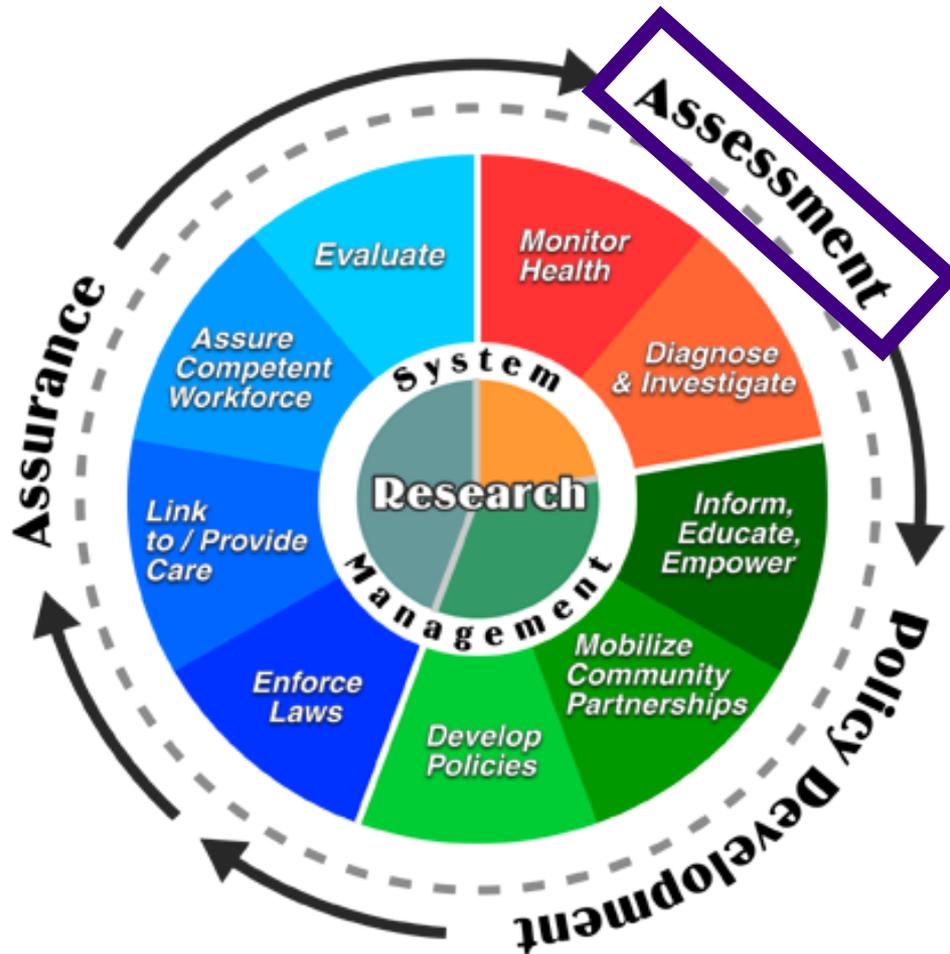
commentary

Core Public Health Functions

- 3 Core Public Health Functions
 - Assessment
 - Policy Development
 - Assurance

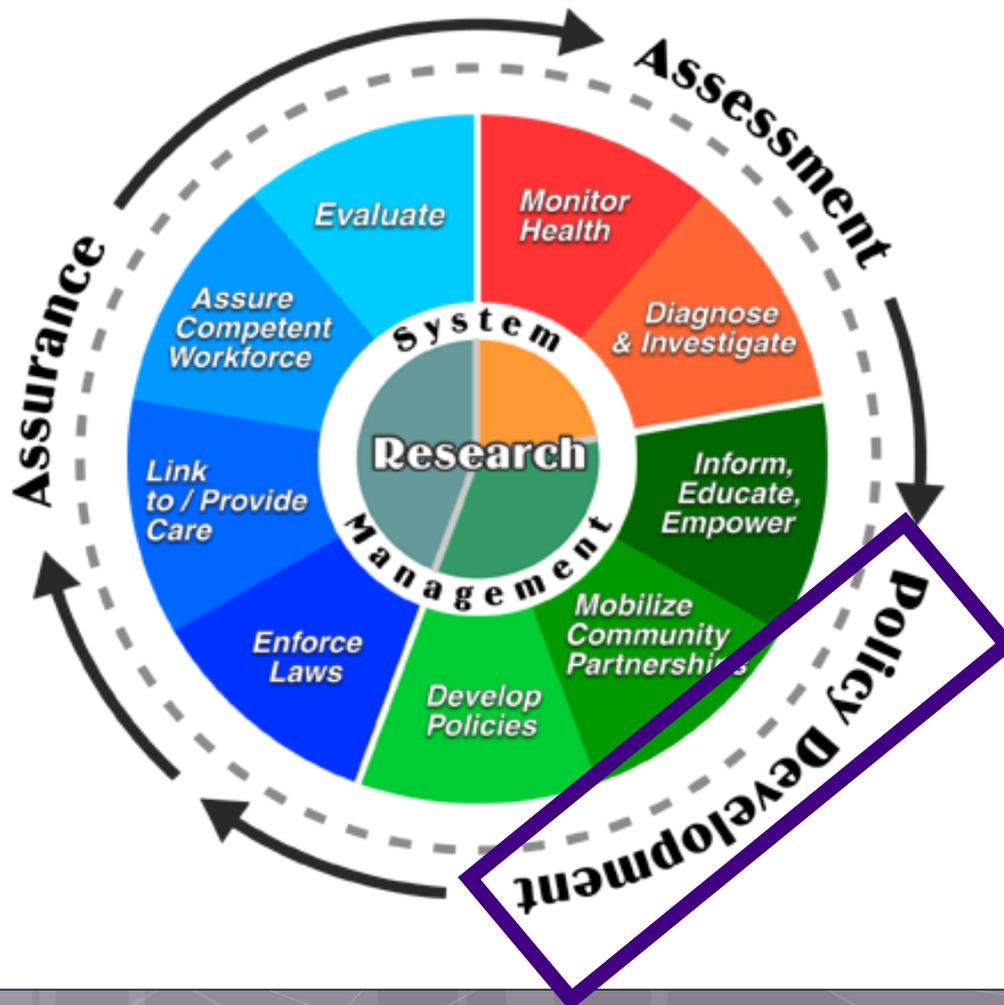


Three Core Public Health Functions and Ten Essential Services



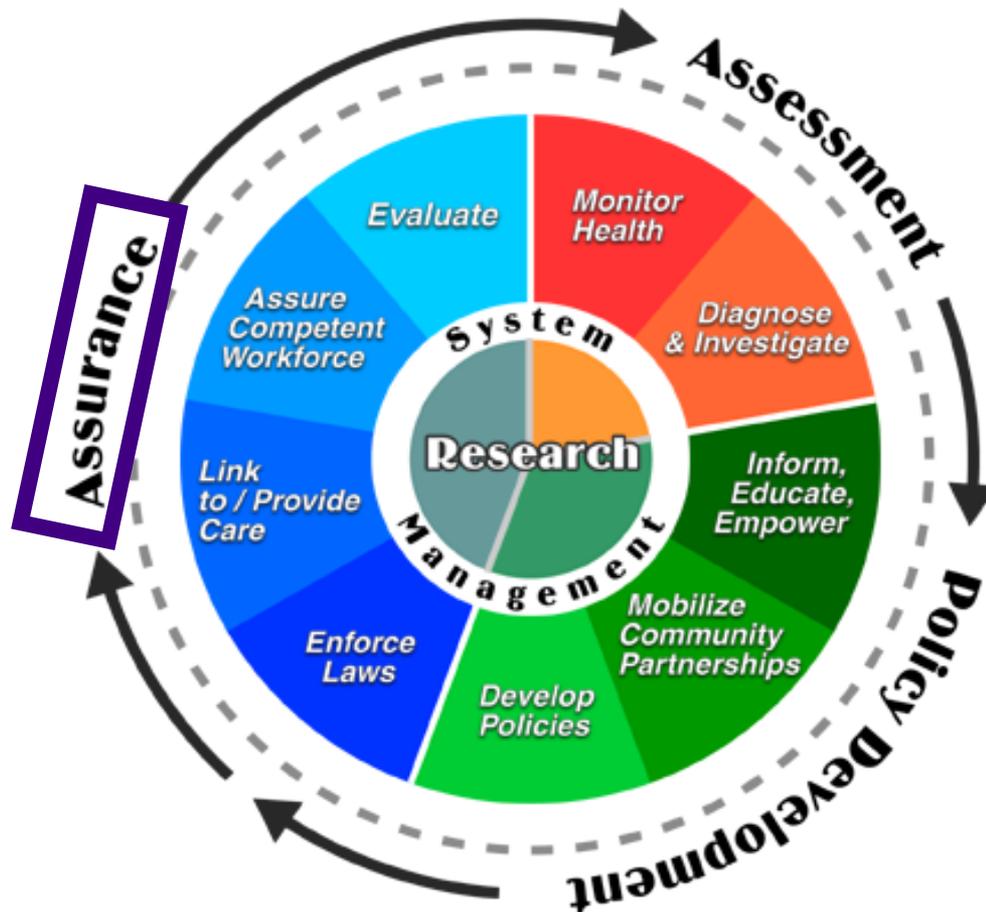
- **Assessment:** The regular systematic collection, assembly, analysis, and dissemination of information, including genetic epidemiologic information, on the health of the community.

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.

Michigan Department of Community Health (MDCH)

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

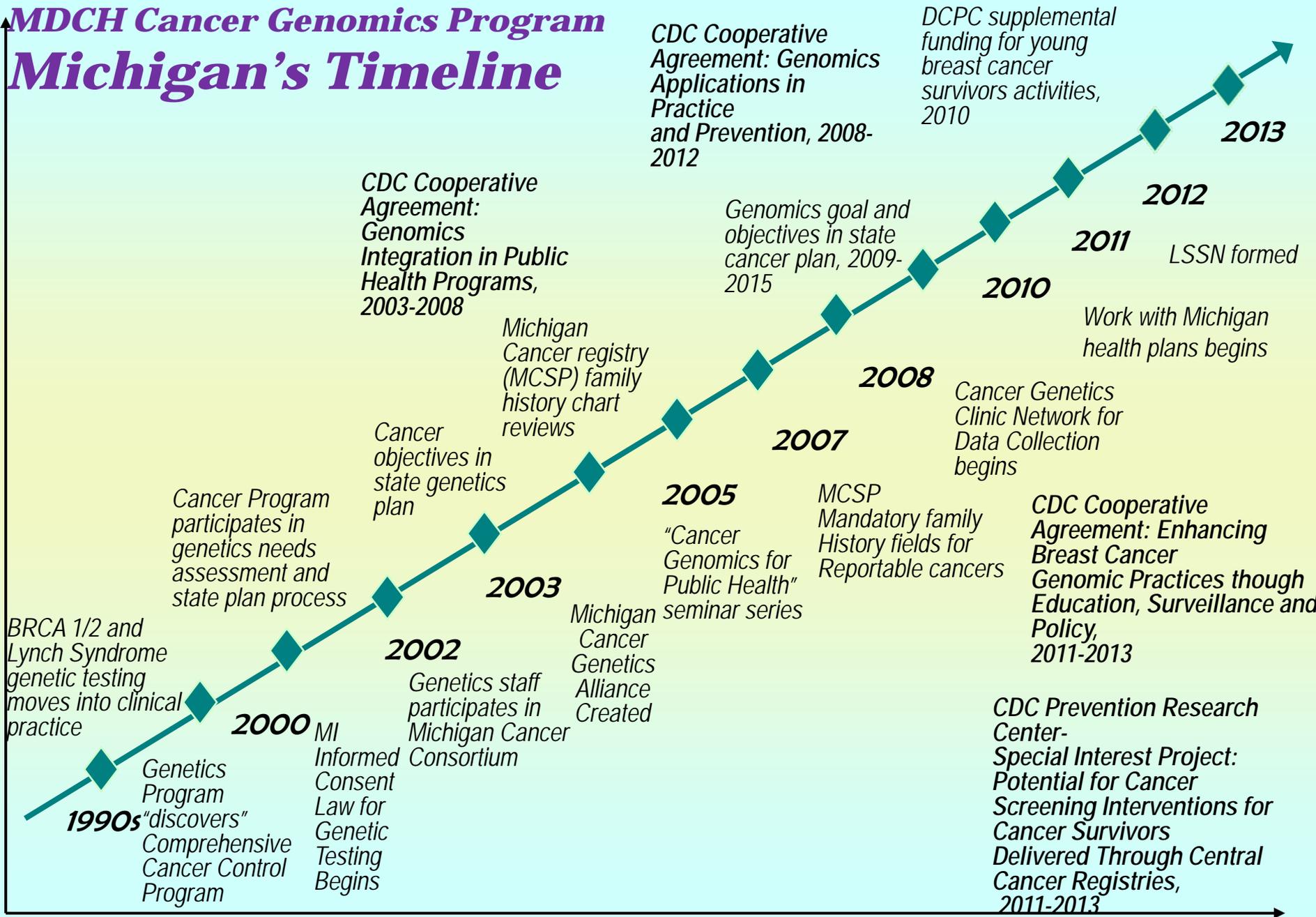
Vision:

Improving the experience of care, improving the health of populations, and reducing per capita costs of health care

Michigan Department
of Community Health

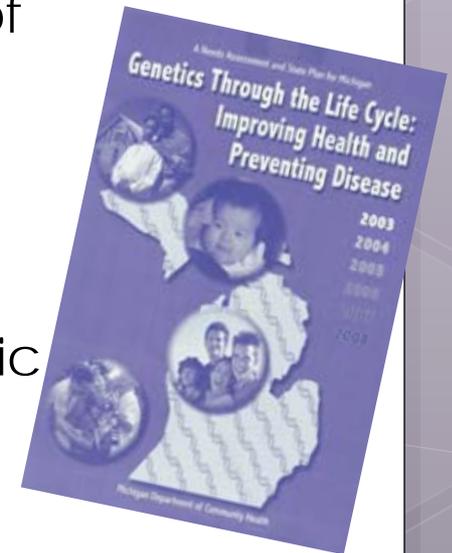


MDCH Cancer Genomics Program Michigan's Timeline



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.*

'What Gets Measured Gets Done'

Genomics and Health Impact Blog

A blog devoted to discussing best practices and questions about the role of genomics in disease promotion and healthcare.

[Public Health Genomics](#) > [Genomics and Health Impact Blog](#)

 Recommend 32  Tweet 12  Share

What Gets Measured Gets Done: Genomics, Surveillance Indicators and Healthy People 2020

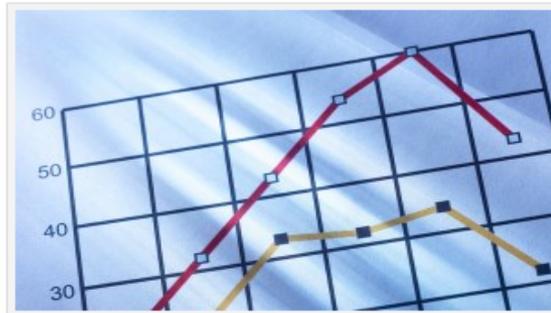
Categories: [genomics](#)

September 13th, 2012 3:00 pm ET - Muin J Khoury, Director, Office of Public Health Genomics, Centers for Disease Control and Prevention

Katherine Kolor, Office of Public Health Genomics, Centers for Disease Control and Prevention

Public health surveillance indicators, such as those developed for the [Healthy People initiative](#) are useful for monitoring the development of genomic medicine in the United States. For several decades, Healthy People has established health benchmarks that are considered important metrics for tracking progress in health and healthcare in the United States.

The Healthy People objectives adopted in 2010 ([HP 2020](#)) introduced a new topic area to address the use of genomic testing in clinical and public health practice. HP 2020 includes two objectives related to genetic counseling and testing for hereditary cancer syndromes.



Healthy People 2020 Genomics 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)

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



Healthy People 2020 Genomics Objectives

The screenshot displays the HealthyPeople.gov website interface. At the top, there is a search bar with the text "Search HealthyPeople.gov:" and a "Go" button. To the right of the search bar are social media icons for Twitter, LinkedIn, and YouTube, along with a "Get E-mail Update" button. Below the search bar is a navigation menu with buttons for "Home", "About Healthy People", "2020 Topics & Objectives", "Implementing Healthy People", "Consortium & Partners", and "Stay Connected".

The main content area shows a breadcrumb trail: "Home > 2020 Topics & Objectives > Genomics". The "Genomics" section is highlighted in red and labeled as "New". To the right of this section are icons for "Print", "E-mail", and "Share". Below this is a tabbed interface with three tabs: "Overview", "Objectives", and "Interventions & Resources", with "Objectives" currently selected.

Under the "Objectives" tab, there are two main sections. The first section is titled "Download all Genomics Objectives [PDF – 10 KB]" and includes an "Expand All Objectives +" button. It lists two objectives:

- G-1** Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling. A "View Details" button is next to it.
- 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). A "View Details" button is next to it.

The second section is also titled "Download all Genomics Objectives [PDF – 10 KB]" and includes another "Expand All Objectives +" button. Below this is a "Back to Top" link.

At the bottom of the page, there is a footer with several links: "About", "Accessibility", "Privacy Policy", "Freedom of Information Act", "Disclaimers", "Contact Us", "Viewers and Players", "Site Map", "Healthy People 2010 Archive", and "Healthfinder.gov". Below the footer is the Healthy People logo and the text "A Federal Government Web site managed by the U.S. Department of Health and Human Services".

- ***“ ... 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

United States Preventive Services Task Force (USPSTF) BRCA Recommendation

2005 Recommendation

- Refer women whose family history is associated with increased risk of BRCA1/2 for genetic counseling and evaluation for BRCA testing
(Grade B)
- Do not routinely refer for genetic counseling or routine BRCA testing for women whose family history is not associated with increased risk of BRCA1/2
(Grade D)

ahrq.gov/clinic/uspstf/uspstfbrgen.htm;
Ann Internal Med 2005;143:355-61 & 362-379

Annals of Internal Medicine

CLINICAL GUIDELINES

Genetic Risk Assessment and BRCA Mutation Testing for Breast and Ovarian Cancer Susceptibility: Recommendation Statement

U.S. Preventive Services Task Force*

This statement summarizes the U.S. Preventive Services Task Force (USPSTF) recommendations on genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility, along with the supporting scientific evidence. The complete information on which this statement is based, including evidence tables and references, is included in the evidence synthesis available through the USPSTF Web site (www.preventiveservices.ahrq.gov). The recommendation is also posted on the Web site of the National Guideline Clearinghouse (www.guideline.gov).

Ann Intern Med. 2005;143:355-361.
For author affiliation, see end of text.

www.annals.org

Individuals who wish to cite this recommendation statement should use the following format: U.S. Preventive Services Task Force. Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility. Ann Intern Med. 2005;143:355-61.

*For a list of the members of the U.S. Preventive Services Task Force, see the Appendix.

SUMMARY OF RECOMMENDATIONS

The U.S. Preventive Services Task Force (USPSTF) recommends against routine referral for genetic counseling or routine breast cancer susceptibility gene (BRCA) testing for women whose family history is not associated with an increased risk for deleterious mutations in breast cancer susceptibility gene 1 (BRCA1) or breast cancer susceptibility gene 2 (BRCA2).

This is a grade D recommendation. (See Appendix Table 1 for a description of the USPSTF classification of recommendations.)

The USPSTF found fair evidence that women without certain specific family history patterns, termed here "increased-risk family history" (see Clinical Considerations for a definition), have a low risk for developing breast or ovarian cancer associated with BRCA1 or BRCA2 mutations. Thus, an

rious mutations in BRCA1 or BRCA2 genes be referred for genetic counseling and evaluation for BRCA testing.

This is a grade B recommendation.

The USPSTF found fair evidence that women with certain specific family history patterns (increased-risk family history) have an increased risk for developing breast or ovarian cancer associated with BRCA1 or BRCA2 mutations. The USPSTF determined that these women would benefit from genetic counseling that allows informed decision making about testing and further prophylactic treatment. This counseling should be done by suitably trained health care providers. There is insufficient evidence to determine the benefits of chemoprevention or intensive screening in improving health outcomes in these women if they test positive for deleterious BRCA1 or BRCA2 mutations. However, there is fair evidence that prophylactic surgery for these women significantly decreases breast

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

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

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



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
- Goals to:
 - **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

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
- **Surveillance central to all activities**
 - *Statewide cancer registry (Michigan Cancer Surveillance Program)*
- 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

Michigan Population and Cancer Genomics

- ◆ **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



Michigan Cancer Surveillance Program (MCSP)

- MCSP has been collecting cancer data since 1985
- Certified by NAACCR (gold standard)
- Funding through vital records fee and CDC NPCR
- 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.



Michigan Cancer Surveillance Program (MCSP)

- Registry established by law (Act 82 of 1984)
 - Cancer and precancerous disease
 - Confidentiality established
 - Endorses uses in research
 - Requires statistical reports
- 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

Indiana Population and Cancer Genomics

- **Public**

- ~6.5 million residents

- **The Indiana State Cancer Registry**

- ~32,500 new reportable cancer cases per year
- National Program of Cancer Registries (NPCR)
- Established by state law

"...in order to conduct epidemiologic surveys of cancer and to apply appropriate preventive and control measures." (IC 16-38-2-1)

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**

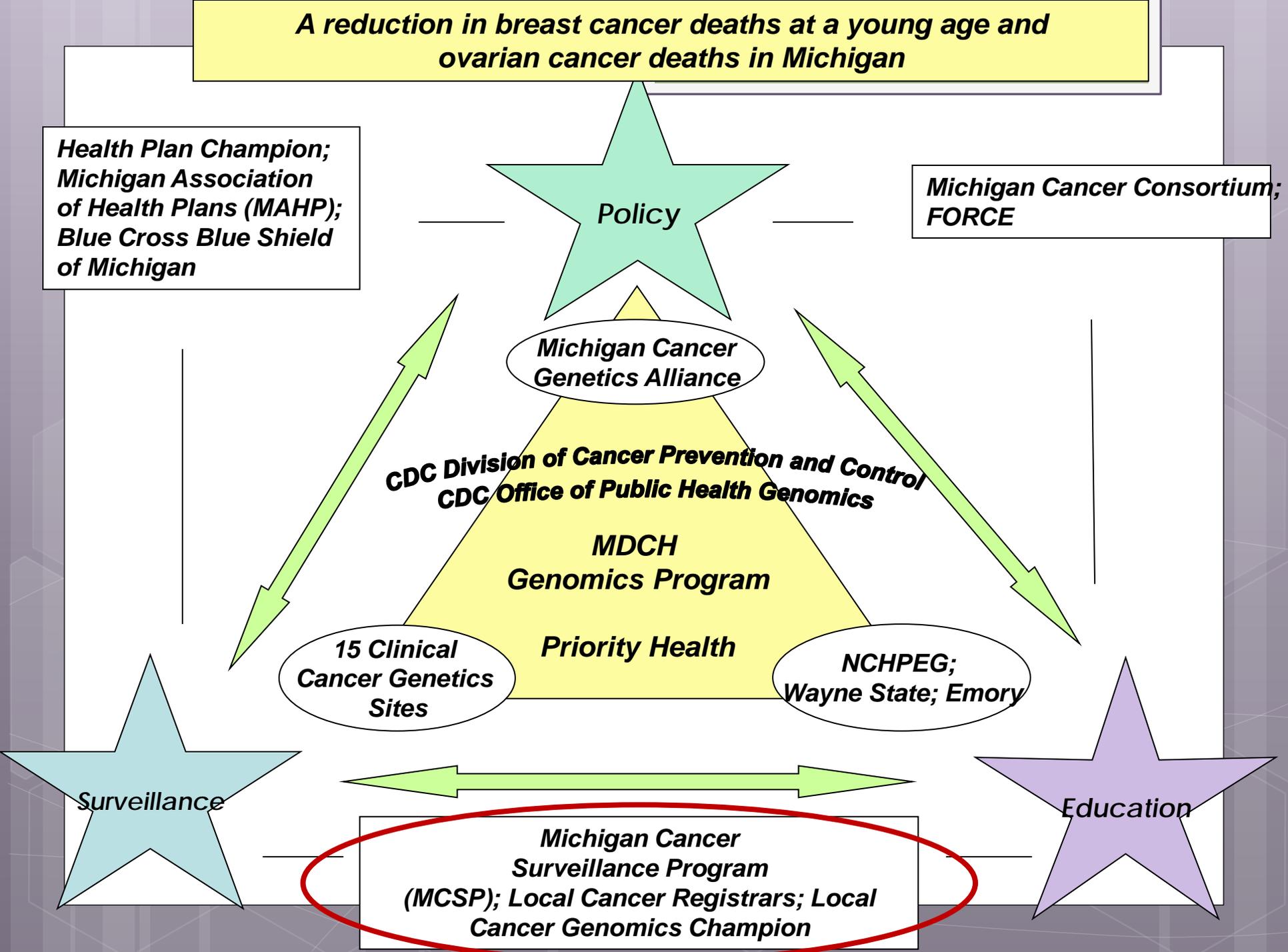
Priority Health

**NCHPEG;
Wayne State; Emory**

Surveillance

Education

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



Michigan Surveillance Objectives, 2008-2011

- 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
- 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

Gene Expression Profiling (GEP) for Breast Cancer Recurrence Risk Prediction, Surveillance in Michigan, 2008-2012

BRCA 1/2 Surveillance in Michigan, 2008-2012

Community Health Program

2012

Michigan Department of Community Health
Cancer Genomics Program

Published September 30, 2012

Examples of Using Cancer Registry Data & Infrastructure for Genomics Surveillance

- **Addition of cancer genetics to quality assurance chart audits**
 - Provider documentation of family history, genetic counseling referral and genetic testing
 - In Michigan, resulted in policy change to mandate family history collection for NPCR cancer registrars
 - Review of 853 cancer charts in 2003-2004
 - 82% documented presence or absence of family history of cancer; 80% documented gender and relationship to patient
 - Of those documenting cancer history, over 94% were missing the age of onset/diagnosis of the affected member's cancer
 - Review of 837 breast cancer charts in 2009-2010
 - Of 332 that met NCCN criteria, only 11 had documentation of genetic counseling; 14 had documentation of BRCA testing with 1 found to have deleterious mutation
 - Review of 137 ovarian cancer charts in 2009-2010
 - 5 had documentation of genetic counseling; 10 had documentation of BRCA testing with 5 found to have deleterious mutation

Examples of Using Cancer Registry Data & Infrastructure for Genomics Surveillance (continued)

- Identification and outreach to cancer patients appropriate for cancer genetic referral
 - Young breast cancer survivors
 - Michigan, Florida, Colorado
- Utilization of existing statewide data through 'genomics lens' to promote cancer genomics best practices
 - Estimates of numbers of cancer patients in state at risk for hereditary cancer syndromes
 - Michigan and Oregon
 - **Bidirectional reporting** to local cancer registry, local health systems and providers
 - Michigan and Connecticut

Examples of Cancer Diagnoses Appropriate for Hereditary Cancer Risk Assessment/Genetic Counseling*

- ✓ Breast cancer diagnosed at a young age (50 years of age or younger)
- ✓ Two breast cancer primaries in a single individual
- ✓ Male breast cancer
- ✓ Ovarian/fallopian tube/primary peritoneal cancer
- ✓ Colorectal cancer
- ✓ Endometrial cancer at a young age (under 50 years of age)
- ✓ Two or more Lynch syndrome-related cancers in a single individual

* *National Comprehensive Cancer Network (NCCN) Guidelines,
2009 EGAPP Lynch Syndrome Recommendation*

Michigan and Oregon Genomics Collaboration to Evaluate Cancer Registries

- Evaluated trends and number and rates of cases from 1997-2007 state cancer registry data
 - Females with early onset breast cancer
 - Males Breast Cancer
 - Colorectal Cancer
 - Early onset endometrial cancer
 - Multiple Primaries



Michigan Department of Community Health
MDCH

Using State Cancer Registries to Evaluate Potentially Hereditary Cancers

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¹Michigan Department of Community Health, Division of Genomics, Perinatal Health and Chronic Disease Epidemiology ²Oregon Genetics Program, Public Health Division ³Oregon State Cancer Registry, Public Health Division ⁴Oregon Health and Science University, Child Development and Rehabilitation Center, Center for Children and Youth with Special Health Needs ⁵Michigan Department of Community Health, Division for Vital Records and Health Statistics



Oregon Health Division

Introduction

The Michigan Department of Community Health (MDCH) and the Oregon Genetics Program, in collaboration with the Centers for Disease Control and Prevention (CDC) Office of Public Health Genomics, are conducting surveillance to promote evidence-based genomics best practices. Data from their respective state cancer registries has been used to increase the understanding of statewide incidence rates and trends related to possible inherited cancers including:

★ BRCAl/2 related cancers ★

Breast
Ovarian

★ HNPCC related cancers ★

Colorectal
Ovarian
Endometrial

Michigan and Oregon both participate in the National Program of Cancer Registries through CDC. The state-based registries collect, manage and analyze data on cancers in their states. These registries collect data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment. Michigan and Oregon are using this large base of data as a potential surveillance method to estimate the need of genetic services in the two states due to residents' personal history of cancer.

Methods

Michigan and Oregon analyzed cancer registry data from 1997-2006. The registry staff identified cases which had a primary cancer that was possibly associated with BRCAl/2 or HNPCC in that time period (i.e. breast, ovarian, colorectal, endometrial). When ovarian cancer is discussed it includes fallopian tube and primary peritoneal cancers with ovarian diagnoses.

Genetic program staff then identified cases that had more than one multiple primary cancer of interest, such as breast-breast or breast-ovarian. These cases were identified for their likelihood of having an inherited cause.

The number of cases were examined and rates were calculated to make the numbers comparable between the states. The rates were age-adjusted to the 2000 U.S. Standard Population. Multiple primary cancer rates were presented as crude rates.

The two states developed specific criteria to identify cancer cases that could be related to either a BRCAl/2 mutation or an HNPCC mutation. Those criteria included:

★ Early-onset cancer diagnoses (before age 50)

★ Males with breast cancer diagnoses

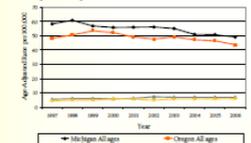
★ Multiple primary cancer diagnoses related to BRCAl/2 or HNPCC

Results

The population demographics in Michigan and Oregon are quite different. In 2008, Michigan had a population just under 10 million residents and reported approximately 64,000 cases of cancer annually, whereas Oregon had under 4 million residents and reported approximately 20,000 cases of cancer annually.

Michigan and Oregon began by examining the incidence trends for each of the primary cancers of interest. Colorectal cancer trends in both states were remarkable when the rates were broken down by age group (Figure 1). The age-adjusted colorectal incidence trend among all ages appears to be decreasing. Michigan saw a decrease of 15.8% in the 10 year period and Oregon saw a 9.2% decrease. However, when the rate was calculated for those under the age of 50 the rates appear to be increasing. Michigan increased by 35.8% and Oregon by 34.1%.

Figure 1. Age-adjusted colorectal cancer incidence rates by age group for Michigan and Oregon, 1997-2006.



As was expected, male breast cancer incidence is very rare in both Michigan (1.5 per 100,000) and Oregon (1.0 per 100,000), however early-onset female breast cancer was much more common (Table 1). In a ten year period Michigan had 15,679 cases of early-onset breast cancer (41.2 cases per 100,000 women), and Oregon had 5,228 cases (41.2 cases per 100,000 women). Michigan had 2,093 cases of early-onset endometrial cancer (5.6 cases per 100,000 women), and Oregon had 556 cases (4.4 per 100,000 women).

Table 1. The numbers and rates for select primary cancers in Michigan and Oregon between 1997-2006

Cancer Type	Michigan N (age-adjusted rate per 100,000)	Oregon N (age-adjusted rate per 100,000)
Breast (Males)	662 (1.5)	170 (1.0)
Early-Onset* Breast (Females)	15,679 (41.2)	5,228 (41.2)
Early-Onset* Endometrial (Females)	2,093 (5.6)	556 (4.4)

*Early-onset is defined as before the age of 50 years

The multiple primary cases were compared between the two states and the rates were very similar except for breast cancer (Table 2). This difference is likely related to Oregon having one of the highest breast cancer rates in the country.

The highest rate of multiple primaries was for breast-breast. Michigan had a rate of 4.9 per 100,000 women and Oregon had a rate of 6.2 per 100,000 women. The second highest number and rate of multiple primaries for both Michigan and Oregon was people with two or more colorectal diagnoses.

Table 2. The numbers and rates for select multiple primaries in Michigan and Oregon between 1997-2006

Cancer Type	Michigan N (crude rate per 100,000)	Oregon N (crude rate per 100,000)
Breast-Breast*	2,490 (4.9)	1,449 (6.2)
Colorectal-Colorectal*	2,234 (2.5)	643 (2.8)
Ovarian-Endometrial*	107 (0.6)	107 (0.6)
Breast-Ovarian*	202 (0.4)	112 (0.6)
Ovarian-Ovarian*	90 (0.2)	15 (0.1)
Endometrial-Endometrial*	109 (0.2)	10 (0.06)
Colorectal-Endometrial*	210 (0.2) (0.4)*	63 (0.2) (0.4)*
Colorectal-Ovarian	103 (0.1) (0.2)*	34 (0.1) (0.2)*

*Rates were calculated using female population only

Discussion

Michigan and Oregon had success in using their state cancer registries to identify trends and incidence rates for specific cancers of genomic interest. To our knowledge this is the first time that multiple primaries have been investigated using state cancer registry data. Michigan has also started to use this data to educate providers about cancer genomics and the population at risk in the state and in their families. Michigan and Oregon plan to continue using this surveillance method as a way to collect information on possible hereditary cancers and to track and evaluate their trends in the future as a measure of their programs' impact.

In the future, both states would like to explore the few differences they had (breast-breast and endometrial-endometrial multiple primaries) to determine the possible reasons for the discrepancies. It would also be helpful to have national statistics to compare with state results. Finally, it is unknown whether these high-risk individuals have received genetic evaluation and counseling and have had a genetic test. An important next step would be to add a required field to the cancer registry on genetic services and/or genetic test results.

The programs concluded that state registries can be used to assess the potential high-risk populations who may benefit from genetic services. The two states had similar rates which indicates this surveillance method could be used more widely by other state health departments or genomics programs for surveillance and educational activities.

This project is supported by Cooperative Agreements # HUSBG000054 and #LUSBG000061 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

http://www.michigan.gov/documents/mdch/MI_OR_Registries2_341754_7.pdf



- ISDH Home
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Indiana State Department of Health



[Chronic Disease](#) > [Cancer Registry](#) > ISCR Statistics Report Generator

ISCR Statistics Report Generator

ISCR Report Generator

You can generate a report based on data from the Indiana State Cancer Registry by making a few simple selections. A report consists of one or more tables that show counts or rates or both for incidence or mortality data. You choose the field for the rows and columns of the tables in the report. The fields you can choose from are the site (or type of cancer), county, age (in 5-year cohorts), race, sex, year (in 1-, 5-, or 10-year groups), and stage at diagnosis.

To protect patient confidentiality, the data available at the county level is limited. These limitations do not apply to the [Public Health Preparedness Districts](#), which are regional groups of counties.

To create a report, click the **Start** button. This displays a page for selecting the data you want in your report. From there you go to a second page for selecting the fields to include in your report. From the second page you generate the report.

To learn more about how to generate a report, click the **Help** button. To see a video demonstration of generating a report, click the **Demo** button. The video requires Flash Player, which you can [download](#) for free.

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- ◆ Indiana Immunization Registry
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4. Find information on recent food recalls
5. Get a Flu Shot



<http://www.in.gov/isdh/24360.htm>

Examples of Indiana Data Publically Available Online

Data compiled by the Indiana State Cancer Registry 28 July 2013.

Data selection:

Type of Data: Incidence
 Geographic Area: State
 Time Period: 1 Year
 Age Adjusted: Yes

Constant fields:

Year: 2011
 Site: Breast

Variable fields:

Row: Race
 Column: Sex

	All Sexes		Males		Females	
	Counts	Rates	Counts	Rates	Counts	Rates
All Races	4,400	61.8	44	1.4	4,356	114.7
White	3,986	61.3	40	1.3	3,946	114.5
Black	347	67.1	3	*1.7	344	117.7
Other	37	19.1	0	*0.0	37	54.6

Rates are per 100,000 population and age-adjusted to the 2000 US Standard Population.
 * Rates based on fewer than 20 cases are unstable.

Data compiled by the Indiana State Cancer Registry 28 July 2013.

Data selection:

Type of Data: Incidence
 Geographic Area: State
 Time Period: 1 Year
 Age Adjusted: Yes

Constant fields:

Year: 2011
 Site: Ovary

Variable fields:

Row: Race
 Column: Sex

	Females	
	Counts	Rates
All Races	423	10.9
White	396	11.2
Black	22	7.9
Other	2	*5.8

Rates are per 100,000 population and age-adjusted to the 2000 US Standard Population.
 * Rates based on fewer than 20 cases are unstable.

Michigan Bidirectional Cancer Registry Reporting: Using Data for Assurance



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.

A Cancer Genetics Profile: Prepared for *Sample*

Focusing on Your Patients' Hereditary Cancer Risk

March 1, 2010



Single Primary Cancers

- Number of cancer cases in 2006-2007 with a diagnosis at any age for the following :
 - Colorectal
 - Male Breast
 - Ovarian
 - Fallopian Tube
 - Primary Peritoneal

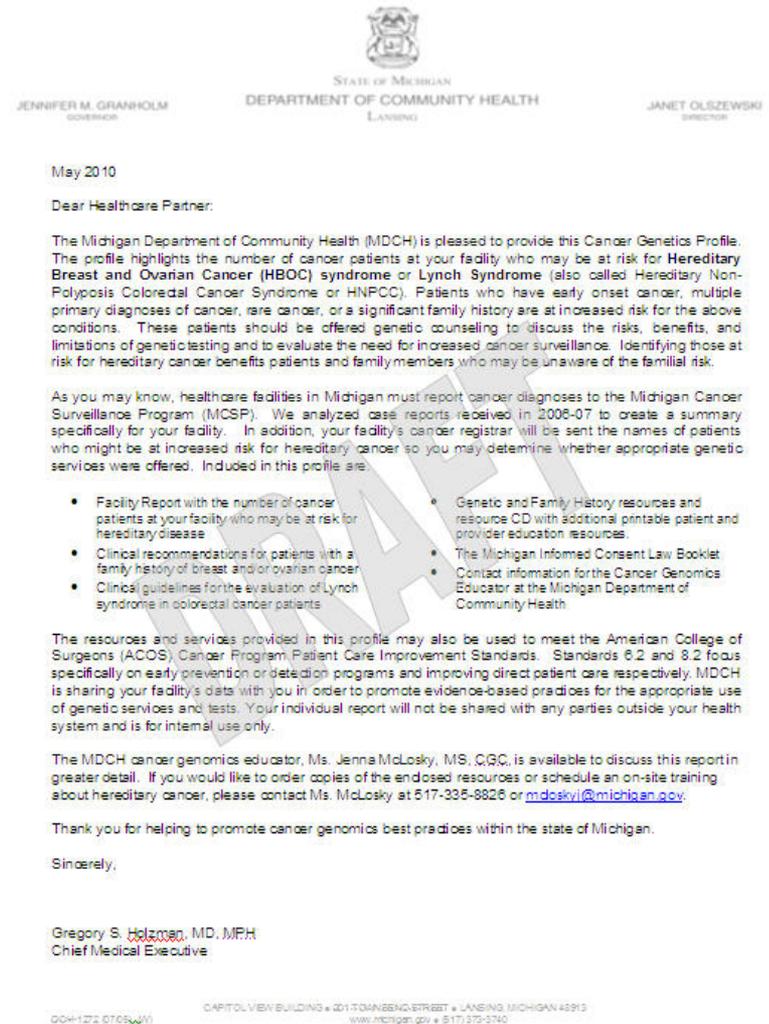
- Number of cancer cases in 2006-2007 with a diagnosis between 18-49 years for the following:
 - Female Breast
 - Endometrial

Multiple Primary Cancers

- 1990-2007 cancer registry data, with at least one diagnosis in 2006 or 2007
- Multiple primaries defined as two or more *BRCA1/2* or Lynch-related cancers that were classified as separate primary tumors
- Examples of multiple primaries:
breast-breast, breast-ovarian, colorectal-endometrial, and colorectal-colorectal
- ***Oregon Cancer Genomics Surveillance Program and Michigan Cancer Genomics worked together to examine single primary cancer and multiple primaries cancers registry data using similar methods***

Facility-Specific Contents

- Introductory letter
- Evidence-Based Recommendations & Guidelines
 - 2005 USPSTF BRCA
 - 2009 EGAPP Lynch Syndrome
 - NCCN Guidelines
- Bidirectional Data Report for Facility
- Directory of Michigan Cancer Genetics Services
- Resource CD, MDCH cancer genomics resources, MDCH new pocket guide
- Assist facility to meet ACOS Cancer Program Patient Care Improvement Standards 6.2 or 8.2
- **Since November 2011 also highlight 2011 ACOS Commission on Cancer New Risk Assessment and Genetic Counseling Standard 2.3**
- Free Provider In-Services Offered



Indiana State Cancer Plan

Objective 3: (Developmental) By 2014, promote monitoring the institutional quality of cancer treatment statewide in Indiana.

Potential data source: National Cancer Data Base

- Develop a way to measure the promotion of monitoring institutional quality of cancer treatment
- Encourage practitioner membership and participation in the Indiana Cancer Consortium
- Encourage all institutions in Indiana that provide cancer care to obtain American College of Surgeons accreditation for their cancer programs
- Promote and increase awareness of the COC

<http://indianacancer.org/wp-content/uploads/2010/04/ICCP-FINAL-1-6-10-3.pdf>

Who received the bidirectional facility-specific reports?

- ✓ 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

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.

Chapter 2: The Case of the Unexpected Syndrome

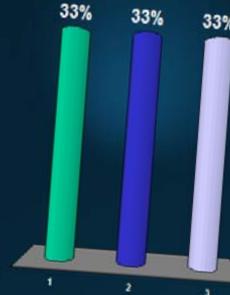
Your patient is a 30-year-old, African American female seen in clinic for her annual check up. She is currently healthy and reports no change in her medical history. Today, her breast exam is negative.

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 "think of."



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).



Chapter 2

- ✓ 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

MCSP 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 four NPCR Michigan facilities affiliated with newly established cancer genetics clinics and providing materials directly to physician

For More Information

Michigan Cancer Genetics Alliance
 Directory of Cancer Genetics Service Providers

Ann Arbor | Battle Creek | Dearborn | Detroit | East Lansing | Farmington Hills | Flint
 Grand Rapids | Grosse Pointe Woods | Kalamazoo | Lansing | Livonia | Mackinac
 Okemos | Royal Oak | St. Joseph Southfield | West Bloomfield

Ann Arbor

Clinic/Office Address	Certification	Types of Cancer
www.migrc.org		
Breast & Ovarian Cancer Risk Evaluation Program University of Michigan Cancer Center 1500 E. Medical Center Dr. Ann Arbor, MI 48109 734.764.0107	Susan M. Wengert, MD, PhD Kara Maron, MS, CGC	X X X
Cancer Genetics Clinic Cancer and Genetics Center University of Michigan Cancer Center 1500 E. Medical Center Dr. Ann Arbor, MI 48109-0630 734.647.2600	Stephen B. Gruber, MD, PhD Stine Stavarin, MS, CGC Jessica E. VanH, MS, CGC Victoria Raymond, MS, CGC Jessica Szymanski, MS	X X X X X

Information on Cancer Genetic Testing and Counseling:

MCGA Guide to the Genetic Testing and Counseling Process
http://www.migeneticsconnection.org/cancer/intro_2.html

MDCH Cancer Genomics Terminology Sheet
<http://www.migeneticsconnection.org/cancer/Terminology.pdf>

Michigan's Informed Consent Law for Genetic Testing
http://www.michigan.gov/documents/InformedConsent_69182_7.pdf

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

US Preventive Service Recommendations on
<http://www.ahrq.gov/clinic/iu> **Or call 1-866-852-1247**

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

Recommendations from the EGAPP Working Group: can tumor gene expression profiling improve outcomes in patients with breast cancer? (2009)
<http://www.egappreviews.org/docs/EGAPPWG-BrCaGePRRec.pdf>

Impact of Gene Expression Profiling Tests on Breast Cancer Outcomes (2008)
<http://www.ahrq.gov/downloads/pub/evidence/pdf/brcancergene/brcangene.pdf>

Tumor Gene Expression Profiling in Women with Breast Cancer
<http://knol.google.com/k/cecilia-bellcross/tumor-gene-expression-profiling-in-39jrm5yo7vhuat7?collectionId=1mzqt0rcvdd.12&position=3#>

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

Michigan.gov
 Department of Community Health
 The Official State Website of Michigan

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

www.michigan.gov/genomics
www.michigan.gov/cge

Methods:
 The core MDCH team includes a project director, coordinator, cancer genomics educator and epidemiologist. In addition, we have identified the partners needed to 1) develop a surveillance system to monitor the use of genetic counseling and testing for BRCA1/2, and the use of genetic tests for colorectal cancer (Lynch Syndrome); 2) implement educational activities; and 3) identify the need for health plan policy changes in relation to the US Preventive Services Task Force Guidelines for the use of BRCA testing. Multiple different activities will address each of these objectives. For further details, please see our [logic model](#).

3) Identifying a model health insurance policy for BRCA1 & 2 cancer genetic testing

Related Content

- Newborn Screening Program
- Michigan Newborn Screening Questions and Answers
- Michigan Bio Trust for Health
- Newborn Screening Follow-up Family Recognition Day September 06, 2009
- Public Health Genomics Program
- Public Health Genomics Program Publications and Presentations
- Birth Defects and Genetic Conditions
- Genomics and Genetic Disorders Staff Directory
- Fact sheets for the eleven NBS disorders

MCC
 Michigan Cancer Consortium

Building bridges with communities and organizations to fight cancer

Spotlight

The Community Network Collaborative Breast Cancer Screening Project is a Detroit Community Network Program project that brings together five organizations to provide breast health awareness, mammography screening, and system navigation to underserved African-American women in the city of Detroit and the surrounding area. [Read more](#) about this award-winning project.

Get to know your family health history

BREAST & PROSTATE CANCER INCOME

Surveillance

Michigan Cancer Surveillance Program (MDCH)

Four Clinical Cancer Genetics Sites

Visit us on
facebook

Follow us on Twitter
 Michigan Cancer
twitter Join the conversation

What We Do

- Visit our [Spotlight Archive](#)
- **www.michigancancer.org**
- [April 18-24 is National Minority Cancer Awareness Week](#)
- [2009 MCC Annual Meeting concurrent session available online as Webinar worth 1.5 CEUs](#)
- [MCC Screening Guidelines for Early Detection of Breast Cancer](#)
- [MCGA IMCC Position Paper for Healthcare Providers: Testing for Hereditary Cancer Predisposition Syndromes and Genetic Counseling](#)
- [Michigan Cancer Survivorship Resource Guide](#)
- [A Survey of Genetic Counselors in Michigan](#)

Connecticut Department of Public Health

- Connecticut successfully replicated and expanded bidirectional process in 2012
 - Received funds through US DHHS-Health People 2020 Action Project
 - Select staff at 31 Connecticut acute care hospitals received bidirectional facility packets with educational materials
 - Invitation for Grand Rounds Training given by board-certified genetic counselor
 - 23 presentations given at 21 hospitals
 - 70% of hospitals reached

Connecticut
Potential Cases of Hereditary Breast and Ovarian Cancer Syndrome
2008-2009

Cancer site	Number of diagnosed cancers
	Connecticut
Female breast (≤50 yrs of age)	1,127
Ovary (All ages)	533
Male breast	47
Multiple primary sites* (Breast-breast or breast-ovary)	2,085

Source: Connecticut Tumor Registry. *The most recent cancer diagnosis was in 2008-2009.

This table contains the number of cancers diagnosed during 2008-2009 in Connecticut patients who could be predisposed to hereditary breast and ovarian cancer syndrome (HBOC).



HBOC is a rare cancer. Most HBOC account ovarian cancer

A woman





Hereditary Breast and Ovarian Cancer Syndrome
Lynch Syndrome



First Example of Bidirectional Reporting for MCSP

- Identify relevant breast, ovarian, colorectal and other cancer cases reported to state cancer registry
- Inform reporting institutions of relevant cancer cases with informational materials about hereditary breast and ovarian cancer and Lynch syndrome
- Generate interests in Grand Rounds to learn more from cancer genetic professionals
- **Michigan** reported back **over 15,000 cases** of cancer relevant to HP 2020 objectives (2007-2008 MCSP data)
- **Connecticut** reported back **over 5,000 cases** of cancer through a Healthy People 2020 Action Award (2008-2009 data)

Michigan 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)
 - Access 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



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.

If you have any questions regarding the study, please contact:
Deb Duquette
Phone: 517-335-8286 Toll Free: 1-866-852-1247
Email: genetics@michigan.gov

If you have any questions about the rights of human research subjects, please contact:
Phone: 517-241-1928
Email: MDCH-IRB@michigan.gov

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: 9/21/2010

IRB expiration date: 9/21/2011

Michigan 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

Michigan 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%)

	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



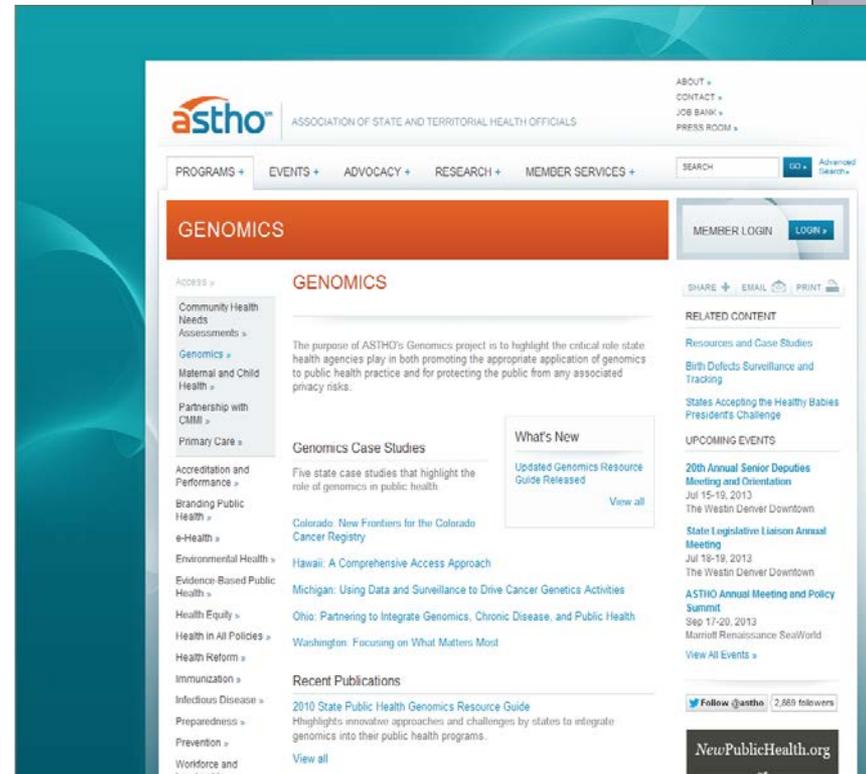
Aim 1: Identify and survey 3,000 YBCS (diagnosed at 20-45 y.o.) to determine breast cancer surveillance utilization and perceived barriers and facilitators to surveillance

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

Colorado Central Cancer Registry & University of Colorado

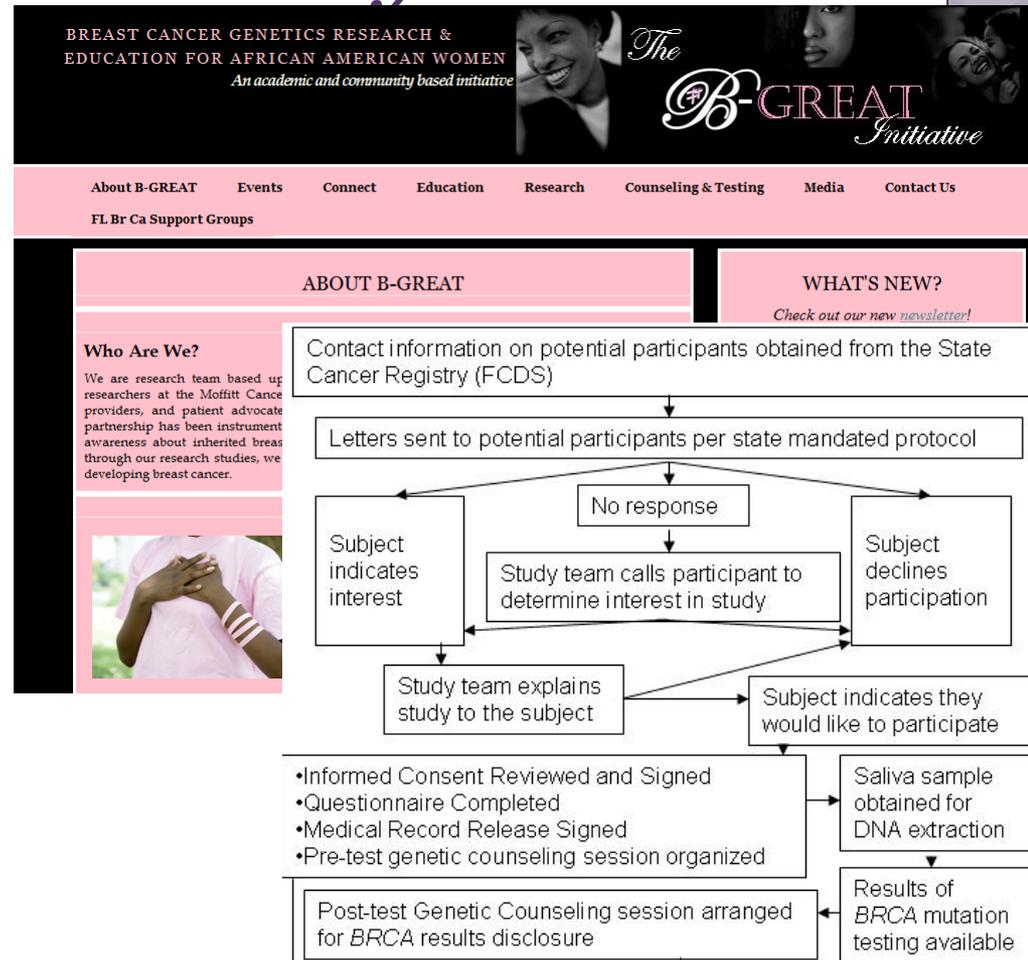
- 2009 project to increase awareness about hereditary colon cancer
 - Received grant from Mountain State Genetics Collaborative
 - Used registry to identify 575 colorectal cancer patients diagnosed in 2001-2005 that met Bethesda criteria
 - Physician consented prior to patient contact
 - Provided educational outreach by mail and phone access to genetic counseling information to 412 physicians and 181 patients



<http://www.astho.org/Programs/Access/Genomics/>

Moffitt Cancer Center & Florida Cancer Data System

- In 2006-2010, conducted study of **inherited breast cancer in young African American women with breast cancer**
 - Funded by Susan G. Komen Foundation
 - Recruited 316 young African American women with breast cancer through Florida Cancer Data System
 - Over 200 received genetic counseling and BRCA testing
 - Found African American women interested and willing to participate in this research



Pal T et al. Recruitment of black women for a study of inherited breast cancer using a cancer registry-based approach. *Genet Test Mol Biomarkers*. 2011 Jan-Feb;15(1-2):69-77. doi: 10.1089/gtmb.2010.0098. Epub 2010 Nov 30.

“...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

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)

All the Michigan Clinical Sites Collaborating on the *BRCA* database

Beaumont Health System Cancer Genetics Program

Cancer Genetics Program at St. Joseph Mercy Hospital-Ann Arbor

Henry Ford Health System

InformedDNA

Karmanos Cancer Institute Genetics Service

Lacks Cancer Center Genetics Program at Saint Mary's Healthcare

Marquette General Hereditary Cancer Program

MidMichigan Health

Michigan State University Division of Clinical Genetics

Oakwood Healthcare System's Genetic Risk Assessment for Cancer Clinic

Providence Hospital Medical Genetics

Spectrum Health Cancer Genetics Program

St. Joseph Mercy Hospital-Pontiac

University of Michigan Cancer Genetics Clinic

University of Michigan Breast and Ovarian Cancer Risk and Evaluation Program

West Michigan Cancer Center



Thank you!

Funding for these projects were made possible by multiple cooperative agreements from the Centers for Disease Control and Prevention. The contents are solely the responsibility of the author and does not necessarily represent the official views of CDC.

