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

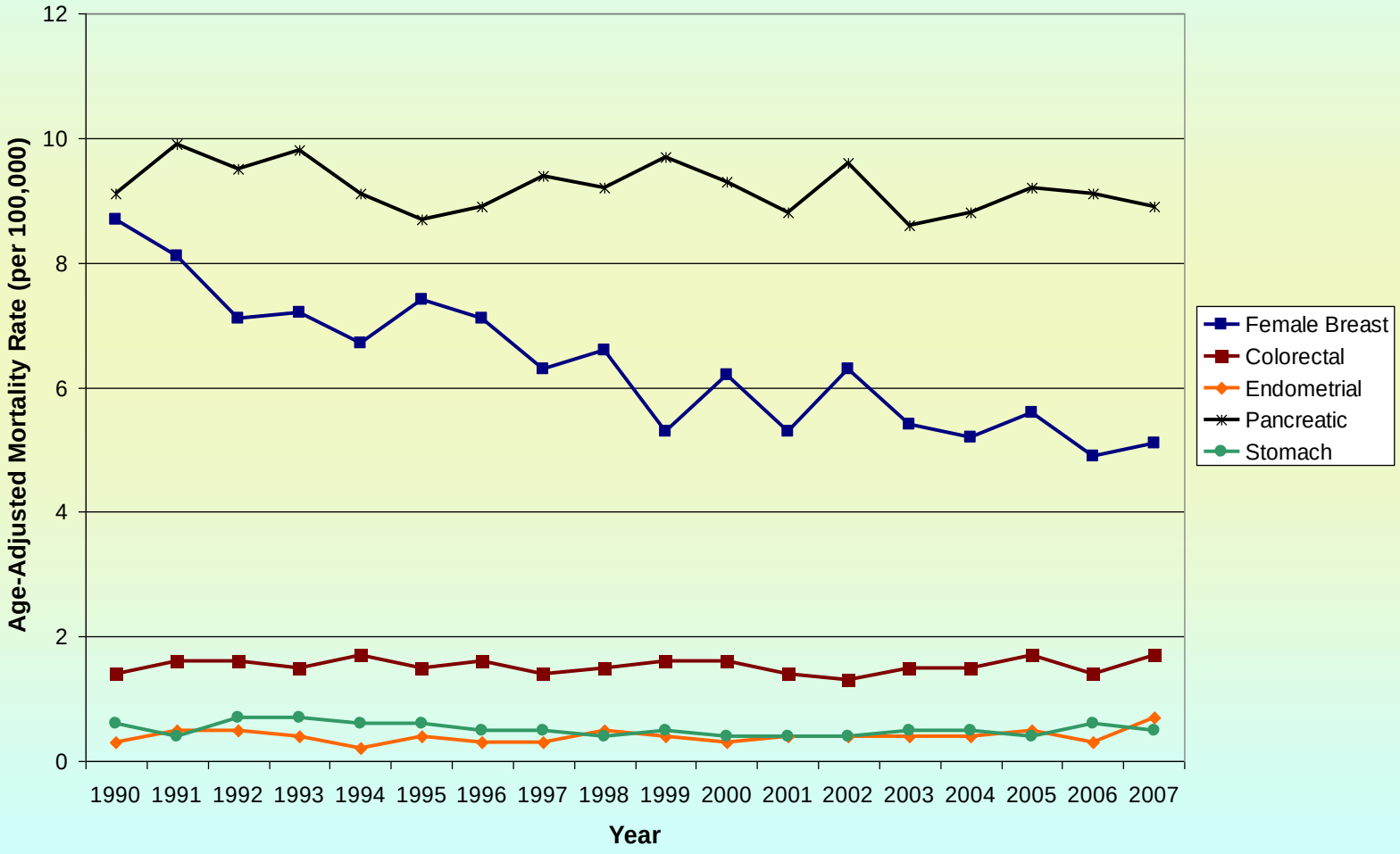
CDC Reverse Site Visit
May 11-12, 2010

Debra Duquette, Janice Bach, Jenna McLosky, Beth Anderson
Michigan Department of Community Health
DuquetteD@michigan.gov

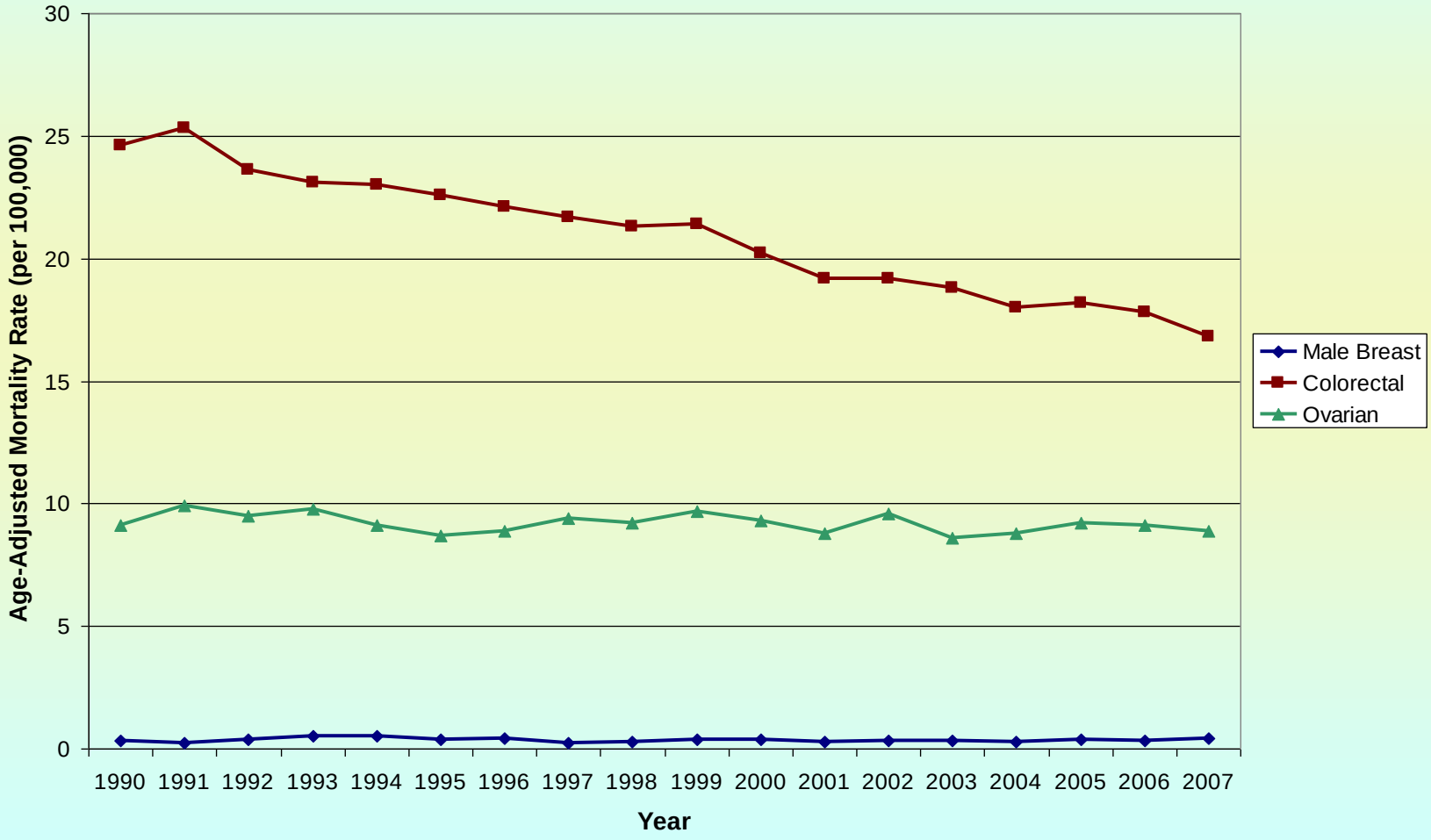
The Ultimate Impact

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

Mortality Rates for Early Onset Cancer (ages 0-49 years) in Michigan

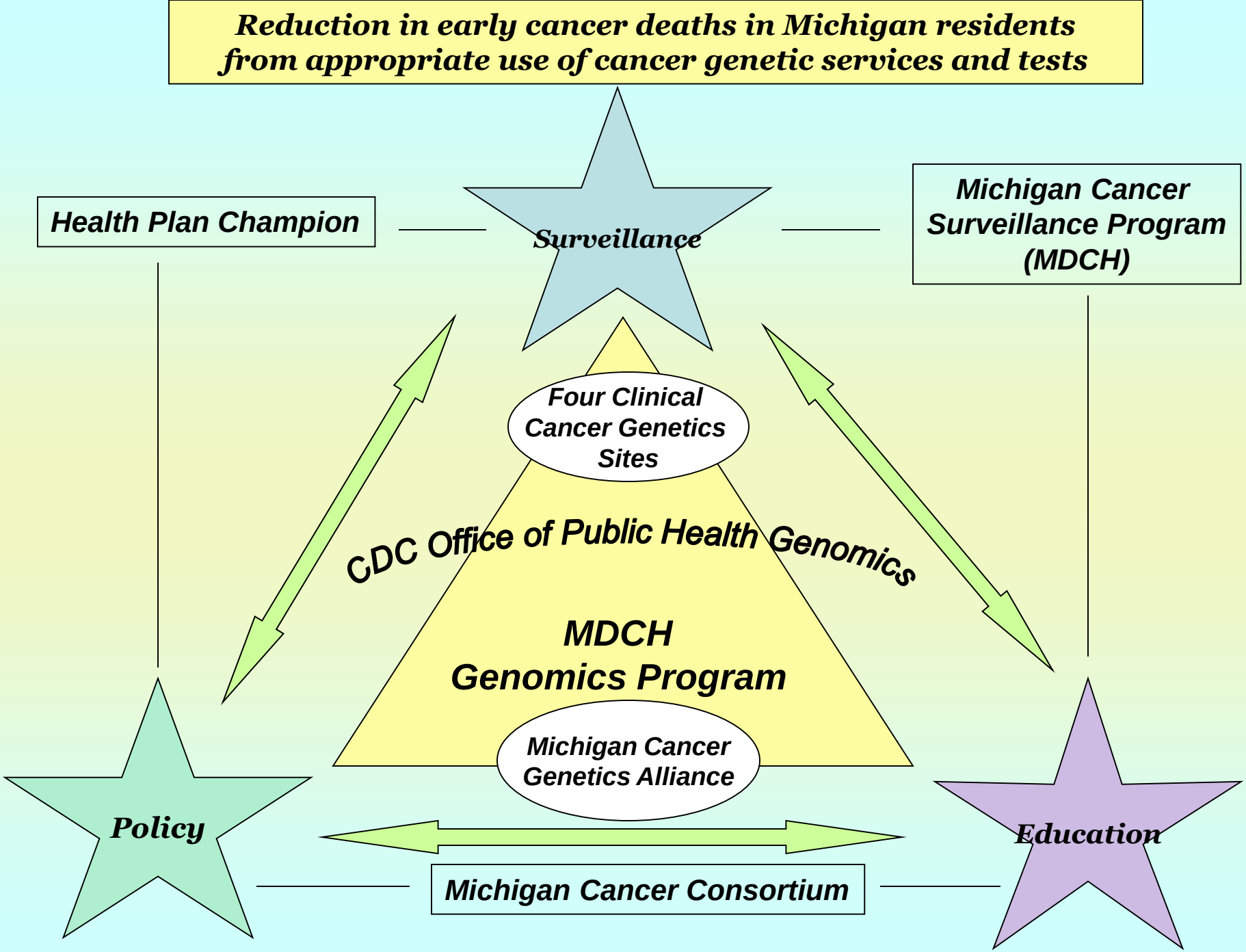


Mortality Rates Among All Ages in Michigan



Our Program's Goals
2008-2011

- 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


Reduction in early cancer deaths in Michigan residents from appropriate use of cancer genetic services and tests
Health Plan Champion
Surveillance
Michigan Cancer Surveillance Program (MDCH)
Four Clinical Cancer Genetics Sites
CDC Office of Public Health Genomics
MDCH Genomics Program
Michigan Cancer Genetics Alliance
Policy
Education
Michigan Cancer Consortium

Target Population

State of Michigan

- **Public**
  - ~ 10 million residents
  - ~ 6.9 million under age 50
- **Health systems and providers**
  - 186 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

Estimate of Potential Michigan Lives Saved Because of BRCA Counseling and Testing

- **Using general population estimates**
  - 7,264 (0.33%) will likely be BRCA positive
    - 6,174 (up to 85% risk of BRCA-related cancer)
    - **5,248 lives saved** (85% or greater risk reduction with surgery)

Potential of ~5,248 to 24,529 Michigan females 18-49 year old lives saved because of BRCA counseling and testing

Ann Internal Med 2005; 143:355-61, 362-79

- **Using USPSTF family history guidelines,**
  - 2,179,089 females ages 18-49 in Michigan in 2008
  - **9.5% (95% CI: 6.9-13.0) of women (ages 18-49) met at least 1 out of 4 USPSTF family history guidelines** (2008 MiBRFS)
  - An estimated **207,013 women** in Michigan are meeting USPSTF guidelines and would benefit from genetic counseling
    - 8,073 to 33,950 women (3.9-16.4%) with BRCA mutation
    - **Potential of 5,833 to 24,529 lives saved**
    - **But, only 10.6% receive genetic counseling and 4.6% genetic testing** (2008 MiBRFS)

Estimate of Potential Michigan Lives Saved Per Year Because of Lynch syndrome Counseling and Testing

- **5,196** Michigan colorectal cancer cases reported per year (2006)
  - Approximately **156** (3%) of those will be caused by Lynch Syndrome
  - If each case has 4 first degree relatives who accept screening and testing, **281 will have the mutation** (45% of first degree relatives with mutation)
    - 112 with CRC (40% risk for CRC)
    - **69 lives saved per year** (62% risk reduction with increased surveillance)
  - If perform cascade testing on 12 first and second degree relatives, **655 will have the mutation** (35% of first and second degree relatives with mutation)
    - 262 with CRC
    - **162 lives saved per year**

Genetics in Medicine 2010; 12:93-104

Potential of ~69 to 162 Michigan lives saved per year

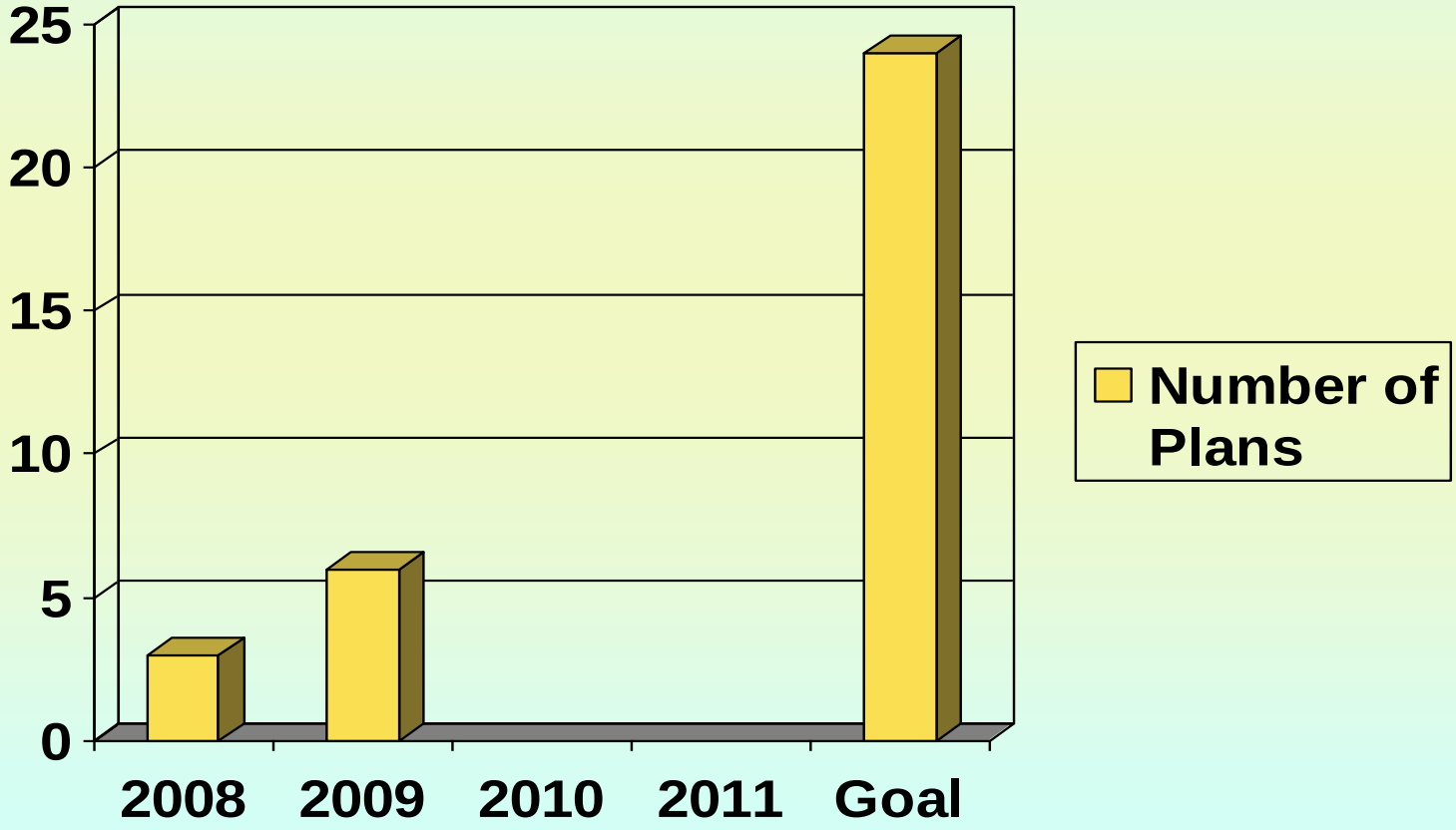
Policy Objectives

- Understand current status of Michigan health insurance policies for BRCA1/2 testing with respect to USPSTF guidelines and related clinical services for BRCA1/2 mutation carriers; and for Lynch syndrome genetic testing with respect to EGAPP recommendations
  - 9 out of 24 health plans with written policies for BRCA coverage
  - Only 6 in alignment with USPSTF recommendations
    - Covers over 6.57 million Michigan residents
    - 1.15 million Michigan residents uninsured (2008)
  - 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

✓ Plan to publish findings in 2011

Health Plan	BRCA1/2 written policy (Y/N)	USPSTF family history criteria (#/8)	Referral to qualified health professional prior to testing (Y/N) * Requires Genetic Counseling	Number of Michigan Members
Aetna	Y (2008)	8/8 (2008)	Y (2008)	280-291,000
Assurant	N			
BCBSM; BCN	Y (4/2009)	6/8 (2009)	Y (2009)	4.6 million; 625,000
Care Source	N			
Cigna	Y (2009)	8/8 (2009)	Y	pending
Grand Valley	N			
Great Lakes	N			
Harrington - Beaumont	Y (2008)	8/8 (2008)	Y (2008)*	34,818
HAP- Henry Ford	Y (2008)	N	Y (2008)*	
Health Plan of MI	N			
HealthPlus	N			
McLaren	N			
Medicaid- MI	N			
Medicare	Y (2008)	N	Y (2008)	
Midwest	N			
Molina	N			
OmniCare	N			
Paramount	Y	6/8 (2008)	N	
Physicians Health Plan	N			
Priority Health	Y (2008)	7/8 (2008); 8/8 (2010)	Y (2008)/(2010)*	450,000
ProCare Health Plan	N			
Total Health Care	N			
Upper Peninsula Health	N			
United Health	Y (8/2009)	7/8 (2009)	Y (2009)	570,000

Number of Michigan Health Insurance Plans Consistent with USPSTF BRCA1/2 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 13 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

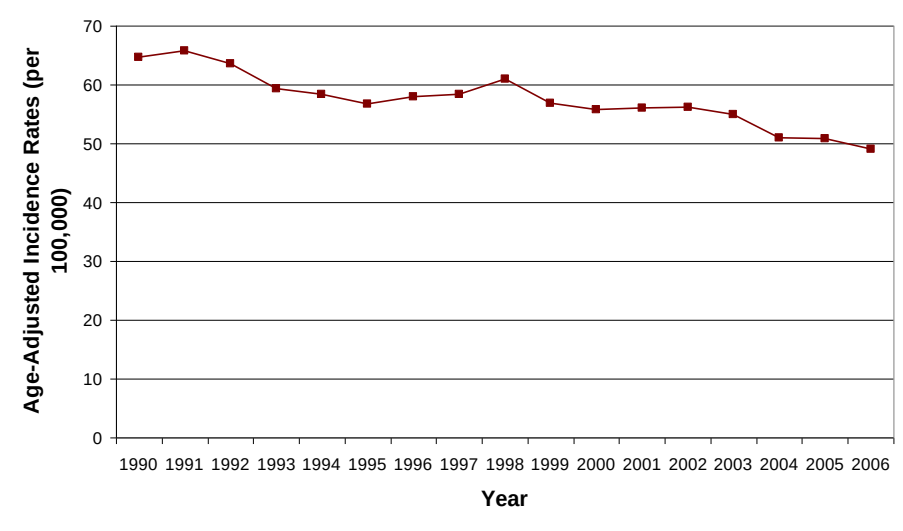
Promote Use of Identified Health Insurance Policy Model

Surveillance Objectives

- To examine the epidemiology of multiple primaries, early onset breast, male breast, ovarian and Lynch syndrome cancers
- To answer questions about 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?
- 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

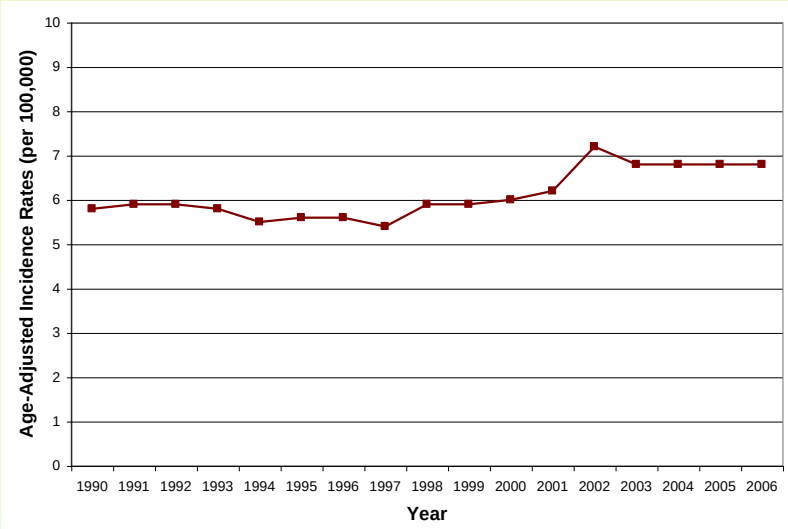
Epidemiology of Colorectal Cancer, All Ages Compared to 0-49 Years

Michigan Age-Adjusted Incidence Rates for Colorectal Cancer by Year, 1990-2006 All Ages



Almost a 25% decrease from 1990 to 2006

Michigan Age-Adjusted Incidence Rates for Colorectal Cancer by Year, 1990-2006 Ages 0-49 years



An increase from 5.8 in 1990 to 6.8 in 2006 but not a *significant* change

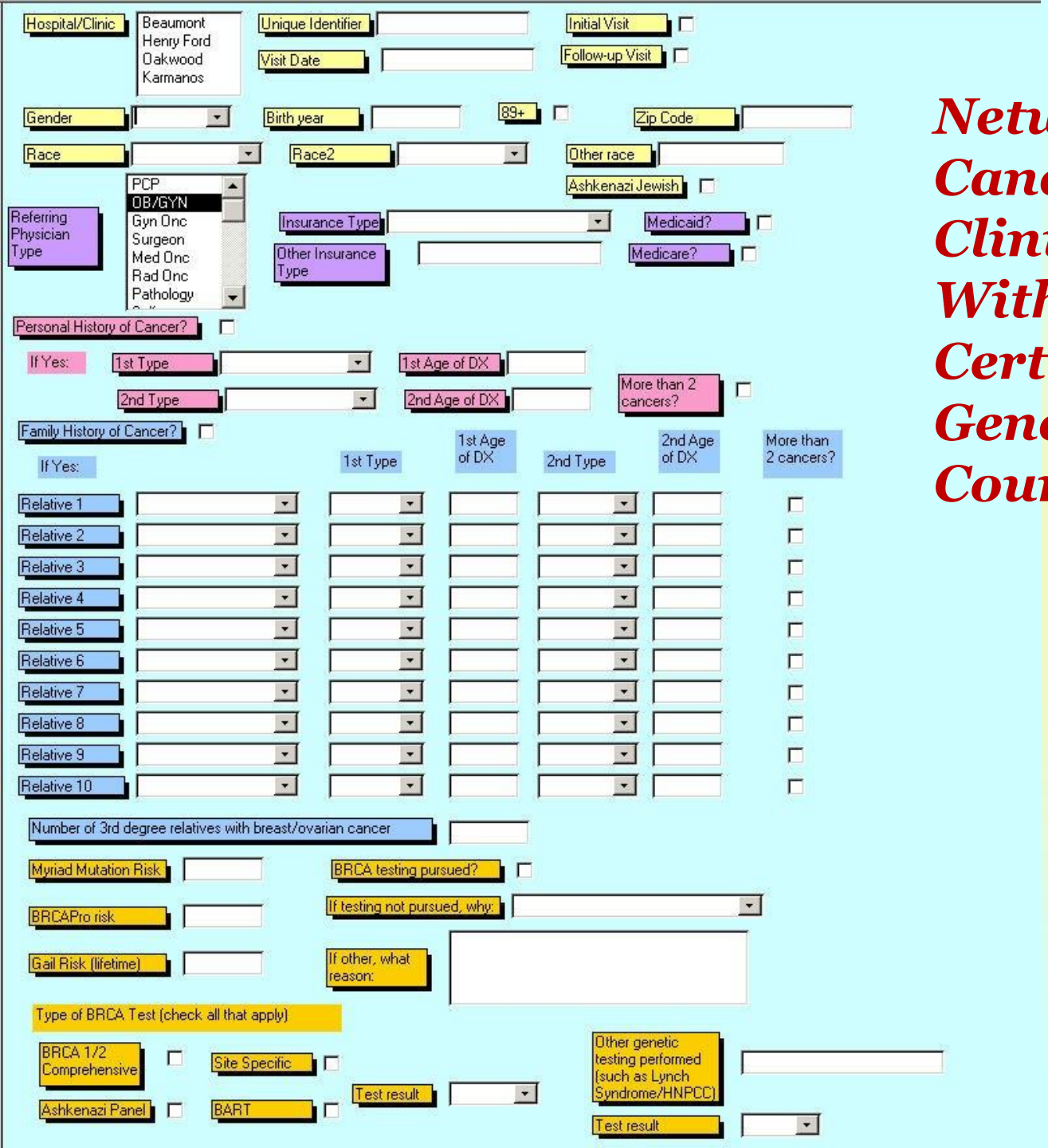
Source: Michigan Resident Cancer Incidence File

Michigan Demographics of Select Multiple Primaries

- Breast-Breast Cases
  - 5,634 people
  - 16 were males
  - 87.7% were white and 11.1% were black
  - 30.4% are deceased

- Colorectal-Colorectal Cases
  - 4,369 cases
  - 53.2% were male
  - 86.2% were white and 12.3% were black
  - 50.8% are deceased

✓ **Plan to Publish MDCH Burden Document in 2010**



Network of Clinical Cancer Genetics Clinics With Board-Certified Geneticist/Genetic Counselors

ACCESS database update coming in **May/June 2010**

Demographics of Patients Accessing BRCA Counseling Services in Four Clinics

Demographic Data from the Four Clinical Sites from October 2007-October 2009*

	Site 1	Site 2	Site 3	Site 4*
	Number (%)	Number (%)	Number (%)	Number (%)
Total Patients	299	307	248	249
Gender				
Male	12 (4.0)	11 (3.6)	5 (2.0)	16 (6.4)
Female	287 (96.0)	296 (96.4)	243 (98.0)	233 (93.6)
Race				
White	230 (76.9)	226 (73.6)	194 (78.2)	228 (91.6)
Black	58 (19.4)	69 (22.5)	19 (7.7)	10 (4.0)
Other	11 (3.7)	12 (3.9)	35 (14.1)	11 (4.4)
Ashkenazi Jewish				
Yes	45 (15.1)	14 (4.6)	3 (1.2)	48 (19.3)
No	254 (84.9)	293 (95.4)	245 (98.8)	201 (80.7)
Referral Type				
Medical Oncologist	65 (21.7)	98 (31.9)	32 (12.9)	42 (16.9)
Surgeon	34 (11.4)	18 (5.9)	58 (23.4)	101 (40.6)
OB/GYN	56 (18.7)	23 (7.5)	59 (23.8)	44 (17.7)
History of Cancer				
Personal History Only	13 (4.3)	21 (6.8)	9 (3.6)	17 (6.8)
Family History Only	129 (43.1)	116 (37.8)	103 (41.5)	89 (35.7)
Personal and Family History	155 (51.8)	169 (55.0)	136 (54.8)	136 (54.6)

*Only 1 year of data from October 2007-October 2008

Patients were included if they had an initial visit at that site, patients who only had follow-up data were excluded.

- Who is accessing cancer genetic counseling services?
- What types of providers are referring?
- Patients were included if they had an initial visit at that site; patients who only had follow-up data were excluded

✓ **Plan to publish in 2011**

Do Health Plan Policies Consistent with USPSTF Influence Visits?

Health Plan	BRCA1/2 written policy (Y/N)	Consistent with USPSTF	Number (%) of Patients at 4 Clinical Sites Receiving Cancer Genetic Counseling	Number of Michigan Members
Aetna	Y (2008)	Y	28 (2.5)	280-291,000
Assurant	N		-	
BCBSM; BCN	Y (4/2009)	Y	560 (51.9)	4.6 million; 625,000
Care Source	N		-	
Cigna	Y (2009)	Y	21 (1.9)	pending
Grand Valley	N		-	
Great Lakes	N		10 (0.9)	
Harrington - Beaumont	Y (2008)	Y	16 (1.5)	34,818
HAP- Henry Ford	Y (2008)	N	246 (22.8)	
Health Plan of MI	N		3 (0.3)	
HealthPlus	N		1 (0.1)	
McLaren	N		-	
Medicaid- MI	N		33 (3.1)	
Medicare	Y (2008)	N	111 (10.3)	
Midwest	N		6 (0.6)	
Molina	N		3 (0.3)	
OmniCare	N		4 (0.4)	
Paramount	Y	N	2 (0.2)	
Physicians Health Plan	N		-	
Priority Health	Y (2008)	Y	8 (0.7)	450,000
ProCare Health Plan	N		-	
Total Health Care	N		4 (0.4)	
Upper Peninsula Health	N		-	
United Health	Y (8/2009)	Y	31 (2.9)	570,000

BRCA Test Results From One Michigan Clinic

Is referral for counseling appropriate using USPSTF family history guidelines? Who is accessing BRCA testing? What are their test results?

•342 included in analysis (excluded males, BART only, known mutations)

–**120 unaffected (35.09%); 62 (51.67%) met USPSTF family history**
- •**46 underwent testing (38.33%)**
  - –Negative: 40 (86.96%)
  - –**Positive: 4 (8.7%)**
  - –Variant: 2 (4.35%)
- •**74 (61.67%) did not pursue testing**
  - –34 (45.95%): not clinically indicated
  - –17 (22.97%): not the best test candidate
  - –7 (9.46%): do not want to know

– **222 affected (64.91%)** (81.8% breast cancer only)
- • **178 (80.18%) underwent testing**
  - – Negative: 159 (89.33%)
  - – **Positive: 9 (5.06%)**
  - – Variant: 9 (5.06%)
  - – **Positive & Variant: 1 (0.56%)**
- • **44 (19.82%) did not pursue testing**
  - – 18 (40.91%): not clinically indicated
  - – 9 (20.45%): inadequate insurance coverage
  - – 7 (15.91%): discuss with relatives

✓ **Plans to Publish in 2010**

Tools to Collect Family History, Genetic Counseling & Testing Through MCSP Chart Reviews

Breast

Cancer Genomics Project
Breast Cancer Abstracting Questionnaire

No.____

1. FACILITY:_____
2. SEX: male / female
3. RACE: _____
4. HISPANIC ORIGIN: yes / no / unknown
5. ASHKENAZI JEWISH: yes / no / unknown
6. OCCUPATION:_____
7. ZIP CODE AT DX:_____
8. SIMULTANEOUS BILATERAL INVOLVEMENT AT DX: Yes ☐ No☐
9. CANCER HISTORY: OVARIAN CANCER Yes ☐ No☐
   BREAST CANCER Yes ☐ No☐
   IF YES, SAME LATERALITY? Yes ☐ No☐
   IF YES, INVASIVE ☐ IN SITU ☐
10. MONTH/YEAR OF DX:_____
11. MONTH/YEAR OF BIRTH:_____
12. AJCC STAGE: 0 / I / II / III / IV
13. LYMPH NODE: positive / negative
14. ERA: positive / negative
15. TUMOR SIZE: ____ (mm)
16. TAMOXIFEN: Yes ☐ No☐
17. CHEMOTHERAPY: Yes ☐ No☐
18. FH OF CANCER? Yes ☐ No☐
19. IF YES, IMMEDIATE FAMILY MEMBER? Yes ☐ No☐
20. IF YES, SAME ANATOMICAL SITE? Yes ☐ No☐
21. NUMBER OF 1ST DEGREE RELATIVES WITH BREAST CANCER: ___
22. NUMBER WITH AGE OF ONSET ≤ 50 ___
23. NUMBER WITH AGE OF ONSET > 50 ___
24. NUMBER UNKNOWN AGE OF ONSET ___
25. 2ND DEGREE RELATIVES WITH BREAST CANCER:_____
26. MALE RELATIVE WITH BREAST CANCER: Yes ☐ No☐
27. 1ST OR 2ND DEGREE RELATIVES WITH OVARIAN CANCER:_____
28. BRCA TESTING Yes ☐ No☐ RESULT: positive / negative / variant
29. GENE EXPRESSION PROFILING:
    Oncotype DX: Yes ☐ No ☐ Not offered ☐ - If yes, TAILORx? Yes ☐ No ☐
    RESULT: Low risk (risk score < 18) ☐ Intermediate Risk (RS 18-30) ☐ High risk (RS≥31) ☐
    MammaPrint: Yes ☐ No☐ Not offered ☐ RESULT: Low risk ☐ High risk ☐
    H:I ratio test: Yes ☐ No☐ Not offered ☐ RESULT: Low risk ☐ High risk ☐

30. Referral for Genetic Counseling?
    Yes ☐
    No ☐

Ovarian

Cancer Genomics Project
Ovarian Cancer/Fallopian Tube Cancer/Primary Peritoneal Cancer Abstracting Questionnaire

No.____

1. FACILITY:_____
2. RACE: _____
3. HISPANIC ORIGIN: yes / no / unknown
4. ASHKENAZI JEWISH: yes / no / unknown
5. OCCUPATION:_____
6. ZIP CODE AT DX:_____
7. CANCER HISTORY: OVARIAN CANCER ☐
   FALLOPIAN TUBE CANCER ☐
   PRIMARY PERITONEAL CANCER ☐
8. PERSONAL HISTORY OF BREAST CANCER: Yes ☐ No☐
9. MONTH/YEAR OF DX:_____
10. MONTH/YEAR OF BIRTH:_____
11. FH OF CANCER? Yes ☐ No☐
12. IF YES, IMMEDIATE FAMILY MEMBER? Yes ☐ No☐
13. IF YES, SAME ANATOMICAL SITE? Yes ☐ No☐
14. BREAST OR OVARIAN CANCER IN ANY 1ST OR 2ND DEGREE RELATIVE: Yes ☐ No☐
15. REFERAL FOR GENETIC COUNSELING: Yes ☐ No ☐
16. BRCA TESTING Yes ☐ No☐ RESULT: positive / negative / variant

Colorectal

Cancer Genomics Project
Colorectal Cancer Abstracting Questionnaire

No.____

1. FACILITY:_____
2. SEX: male / female
3. RACE: _____
4. HISPANIC ORIGIN: yes / no / unknown
5. OCCUPATION:_____
6. ZIP CODE AT DIAGNOSIS:_____
7. CANCER HISTORY: prior colorectal / prior or synchronous HNPCC related cancer†
10. MONTH/YEAR OF DX:_____
11. MONTH/YEAR OF BIRTH:_____
12. AJCC STAGE: 0 / I / II / III / IV
13. PRIMARY SITE:_____
14. FH OF CANCER? Yes ☐ No☐
15. IF YES, IMMEDIATE FAMILY MEMBER? Yes ☐ No☐
16. IF YES, SAME ANATOMICAL SITE? Yes ☐ No☐
17. NUMBER OF 1ST DEGREE RELATIVES WITH HNPCC RELATED CANCERS: ___
18. NUMBER WITH AGE OF ONSET ≤ 50 ___
19. NUMBER WITH AGE OF ONSET > 50 ___
20. NUMBER UNKNOWN AGE OF ONSET ___
21. 2ND DEGREE RELATIVES WITH HNPCC RELATED CANCER:_____
22. MSI-H HISTOLOGY
    TUMOR INFILTRATING LYMPHOCYTES: Yes ☐ No☐
    CROHN'S-LIKE LYMPHOCYTIC REACTION: Yes ☐ No☐
    MUCINOUS/SIGNET-RING DIFFERENTIATION: Yes ☐ No☐
    MEDULLARY GROWTH PATTERN: Yes ☐ No☐

24. Referral for Genetic Counseling?
    Yes ☐
    No ☐

23. TESTING ASSOCIATIED WITH HNPCC (LYNCH SYNDROME)

Test	Performed		Result			
Microsatellite Instability (MSI)	Yes ☐	No ☐	MSI-high ☐	MSI-low ☐	MSS (no instability) ☐	
Immunohistochemistry (IHC)	Yes ☐	No ☐	MLH1: Present ☐ Absent ☐	MSH2: Present ☐ Absent ☐	MSH6: Present ☐ Absent ☐	PMS2: Present ☐ Absent ☐
BRAF*	Yes ☐	No ☐	V600E MUTATION: Positive ☐ Negative ☐			
Mismatch repair (MMR)	Yes ☐	No ☐	RESULT: Positive ☐ Negative ☐ Variant ☐ IF POSITIVE, WHICH GENE? MLH1 ☐ MSH2 ☐ MSH6 ☐ PMS2 ☐			

* BRAF testing is typically conducted when MLH1 is absent on IHC testing.

†**HNPCC (Lynch syndrome) associated cancers:**
colorectal, endometrial, ovarian, duodenal/small bowel, gastric, ureteral/renal pelvis, sebaceous adenomas or carcinomas, keratoacanthomas, hepatobiliary/pancreas, brain

Surveillance

Resources

- USPSTF BRCA Recommendations
- EGAPP Lynch & Gene Expression Guidelines
- Michigan Cancer Genetics Alliance
- MDCH Genomics Program
- Michigan Cancer Surveillance Program (MCSP)
- Four Clinical Cancer Genetics Sites

Activities

- ✓ Examine existing cancer registry data to monitor early onset, multiple primary and male breast cancer incidence rates, trends, and mortality
- ✓ Collect and analyze data on use of family history, genetic counseling, and testing through MCSP chart reviews
- ✓ Form a network with thirteen clinical sites to collect and share data on referrals and use of BRCA testing and follow-up decisions and care after testing positive for a known or variant mutation
- ✓ Survey cancer survivors to assess barriers and facilitators to knowledge, attitudes, and use of genetic counseling and testing
- ✓ Explore feasibility of linking clinical sites BRCA positive patients with MCSP
- ✓ Investigate feasibility of using Medicaid claims to determine number of colorectal cancer patients having Lynch syndrome pre-testing or genetic testing
- ✓ Use BRFS to conduct surveillance on family and personal history of breast, ovarian and colorectal cancer and genetic services

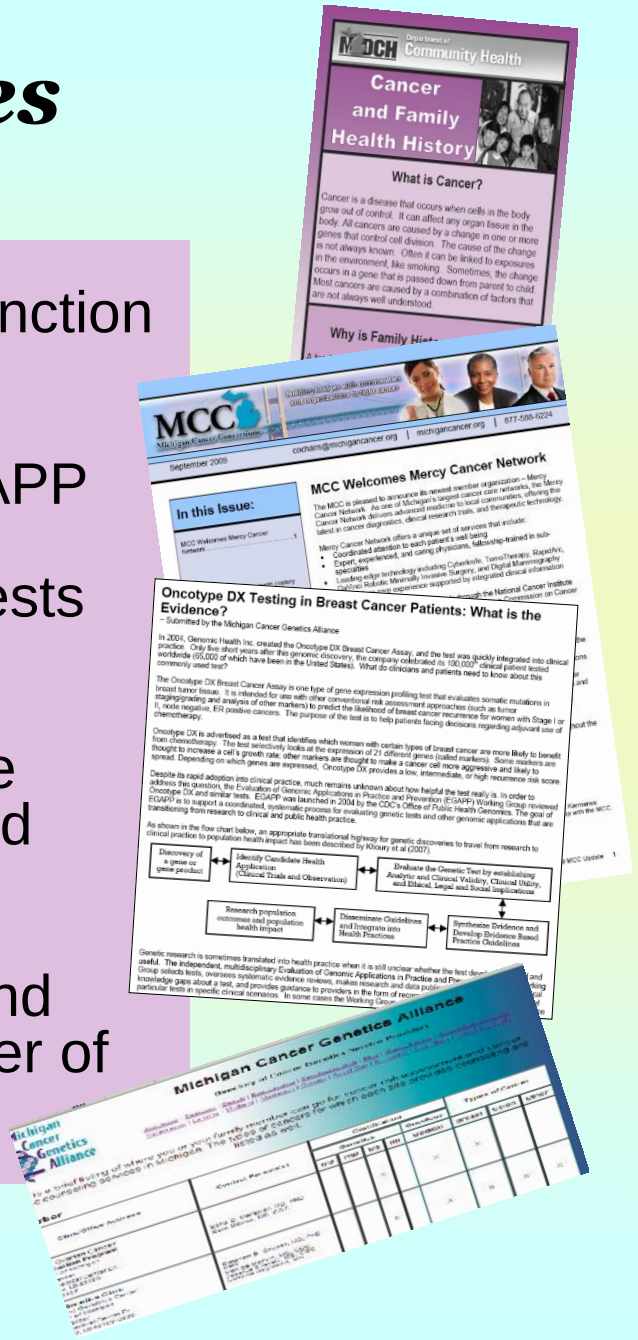
Performance Measure

★ A system for surveillance of BRCA 1/2, Lynch syndrome, and tumor profiling tests; with increased understanding of provider practices and patient knowledge

Promote Use of Model Surveillance System

Education Objectives

- Use statewide surveillance data in conjunction with USPSTF and EGAPP guidelines
- Increase provider awareness about EGAPP recommendations for Lynch syndrome/ HNPCC and gene expression profiling tests for early stage breast cancer
- Increase use of USPSTF clinical practice guidelines for BRCA risk assessment and testing
- Change provider knowledge, attitudes and intentions to ultimately reduce the number of early cancer deaths



Education

Resources

- USPSTF BRCA Recommendations
- EGAPP Lynch & Gene Expression Guidelines
- Michigan Cancer Consortium
- Michigan Cancer Genetics Alliance
- MDCH Genomics Program
- Audience Response System

Activities

- ✓ Disseminate reports to hospitals on the number of potential patients needing BRCA, Lynch and gene expression profiling tests, based on MCSP data
- ✓ Disseminate USPSTF and EGAPP guidelines, written materials, risk assessment tools, website resources, and cancer genetic provider directory
- ✓ Provide free technical assistance to providers
- ✓ Provide free in-service presentations

Performance Measures

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

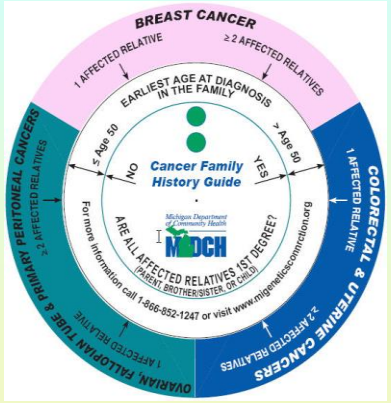
★ Knowledge of validity, utility, harms and benefits of Lynch syndrome and gene expression profiling tests increases from baseline

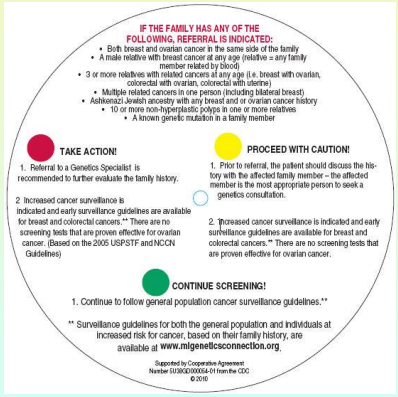
Promote Use of Model Provider Health Education Program

Developing a Provider Tool

Background Surveillance Data

- Approximately 94-98% of reviewed Michigan medical charts do not have a documented age of cancer diagnosis for affected family members
- Key informant interview reveal many Michigan providers:
  - Feel that they do not see patients with high-risk cancer family history
  - Do not feel confident in ability to identify high-risk family history
  - Uncertain where to refer





Public Health Action

- Used USPSTF and EGAPP guidelines (along with NCCN), to develop a new pocket tool for providers
- Four provider focus groups held (family medicine and oncology); unanimous agreement that tool would be used in practice
- The tool assists providers in:
  - Collecting cancer family history
  - Assessing the risk of hereditary cancer
  - Proceeding with referral and/or increased surveillance based on recommendations

Facility-specific Profiles

Michigan Department of Community Health

MDCH

Jennifer M. Granholm, Governor
Janet Olszewski, Director

Public Health Genomics

A Cancer Genetics Profile: Prepared for Oakwood Hospital

Focusing on Your Patients' Hereditary Cancer Risk

March 1, 2010

Michigan Department of Community Health
MDCH
Jennifer M. Granholm, Governor
Janet Olszewski, Director

201 Townsend St. P.O. Box 30195 Lansing, MI 48909

Draft Hospital and Medical Center 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 your facility with feedback on patients reported by your institution at greatest risk for HBOC syndrome and 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 risks and benefits of genetic testing.** HBOC accounts for approximately 5-10% of all breast cancer diagnoses. This condition is also associated with increased risk for ovarian cancer. Approximately 3-5% of all individuals with colorectal cancer will have Lynch Syndrome. This condition is also associated with an increased risk for endometrial and ovarian cancers. Therefore proper recording 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 cancers syndromes and should be managed appropriately.

Table 1. Age 18-49 at diagnosis	*Oakwood 2006 - 2007*	*Michigan 2006 - 2007*
Breast (female)		
Endometrial		

Table 1. number of early onset breast and endometrial cases within your health system and within Michigan.

Table 2. All ages	*Oakwood 2006 - 2007*	*Michigan 2006 - 2007*
Breast (male)		
Colorectal		
Ovarian		

Table 2. number of colorectal and ovarian cancer cases within your health system and within Michigan.

Table 3. All ages	*Oakwood 2006 - 2007*	*Michigan 2006 - 2007*
Multiple primary cancer diagnoses		

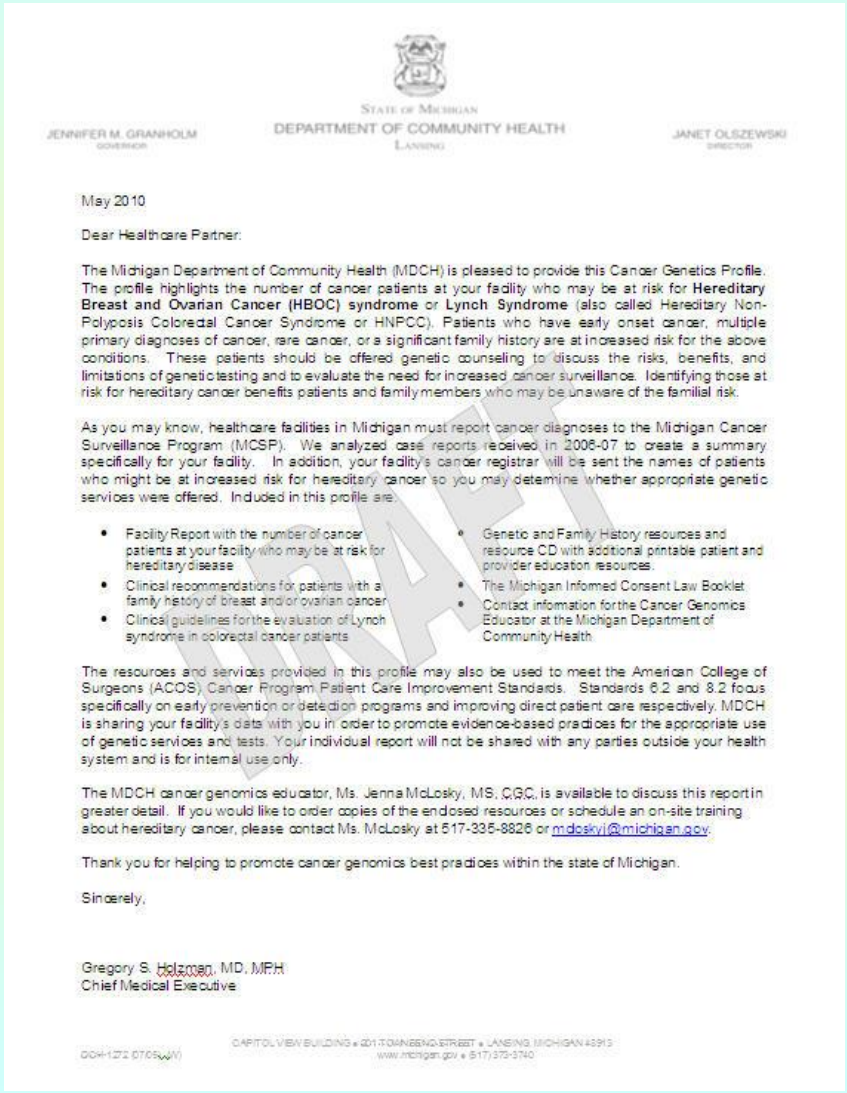
Table 3. number of cases with multiple cancer diagnoses including: breast-breast, breast-ovarian, ovarian-ovarian, colorectal-colorectal, colorectal-endometrial, colorectal-ovarian, endometrial-endometrial, ovarian-endometrial.

** All ovarian cancer data include those cases diagnosed with fallopian tube cancer or primary peritoneal cancer as well.

Prepared on March 1, 2010 by MDCH staff

Contents

- Introductory letter
- Guidelines
  - USPSTF
  - EGAPP
  - NCCN
- 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



STATE OF MICHIGAN
DEPARTMENT OF COMMUNITY HEALTH
LANSING

JENNIFER M. GRANHOLM
GOVERNOR

JANET OLSZEWSKI
DIRECTOR

May 2010

Dear Healthcare Partner:

The Michigan Department of Community Health (MDCH) is pleased to provide this Cancer Genetics 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 (MCSP). We analyzed case reports received in 2006-07 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 (ACOS) 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 517-335-8826 or mdcskyj@michigan.gov.

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

Sincerely,

Gregory S. Holzman, MD, MPH
Chief Medical Executive

DRAFT

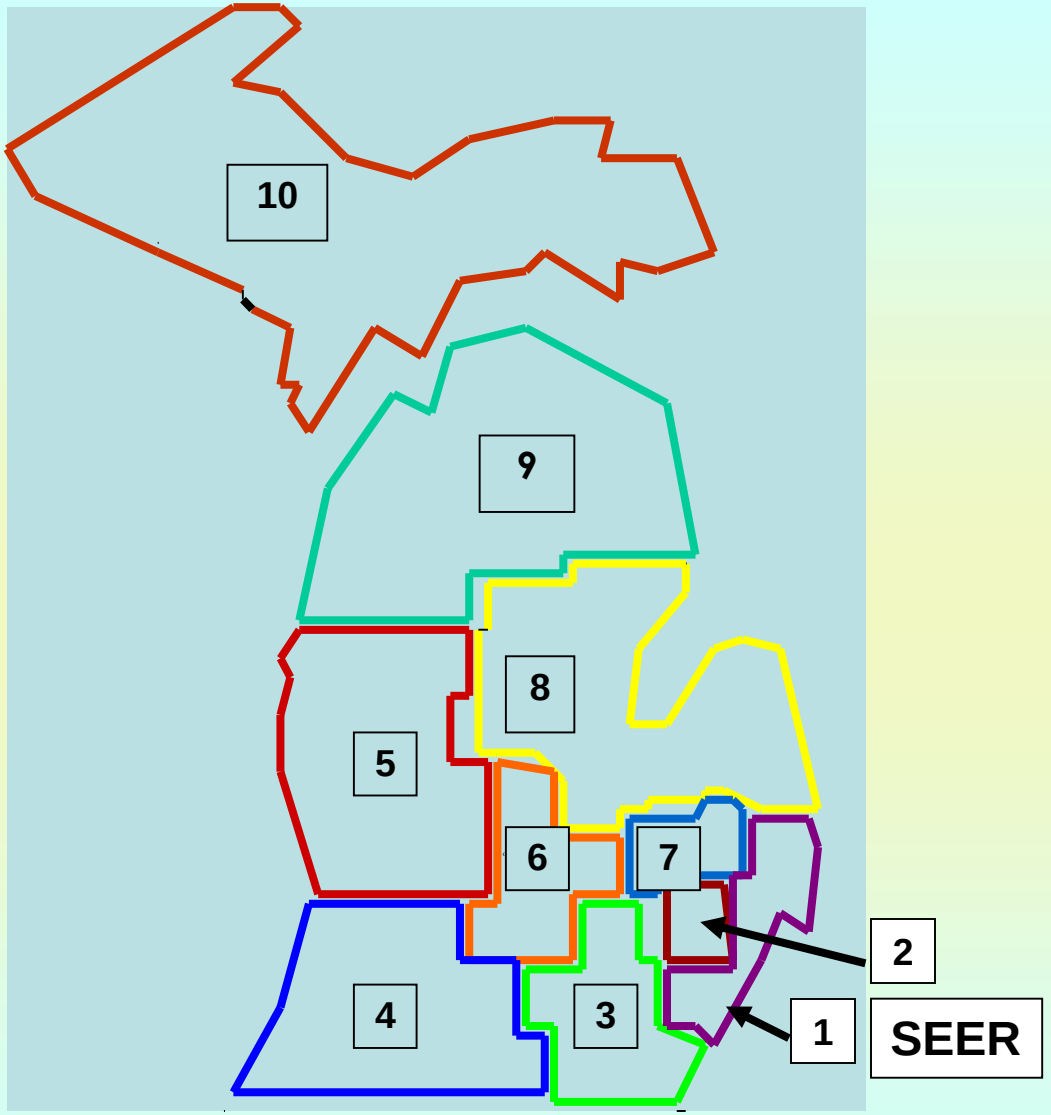
CAPITOL VIEW BUILDING • 201 TOWNSEND STREET • LANSING, MICHIGAN 48913
www.michigan.gov • 517-373-3740

DCH-1272 (07/09)(W)

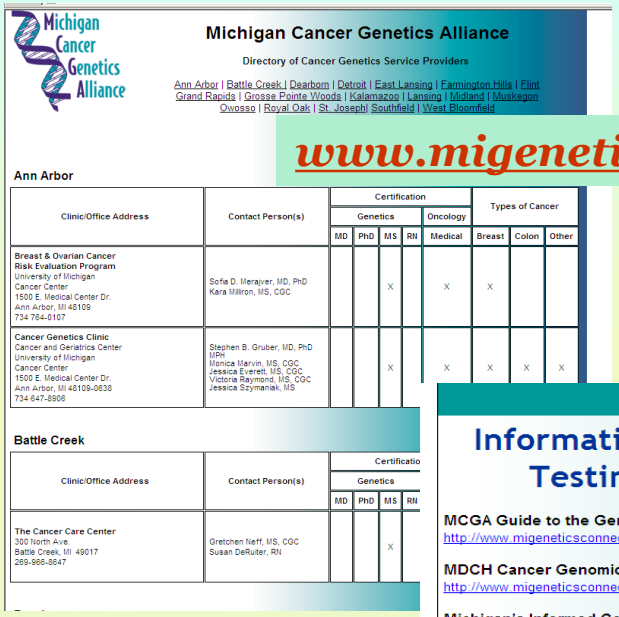
Dissemination of Facility Reports

- Using registry data, we are generating facility specific reports for all non-SEER facilities in 2010; SEER in 2011

- Dissemination will occur by region
  - Region 3 in May 2010
  - Regions 6/7 in June 2010
  - Region 5 in Sept 2010
  - Region 4 in Oct 2010
  - Region 8 in Nov 2010
  - Region 9/10 in Dec 2010



Websites



www.migeneticsconnection.org

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 Services Task Force (USPSTF) Evidence Based Recommendations on BRCA testing for breast cancer
http://www.ahrq.gov/clinic/uspstf/uspstopics.htm

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-BrCaGEPRec.pdf

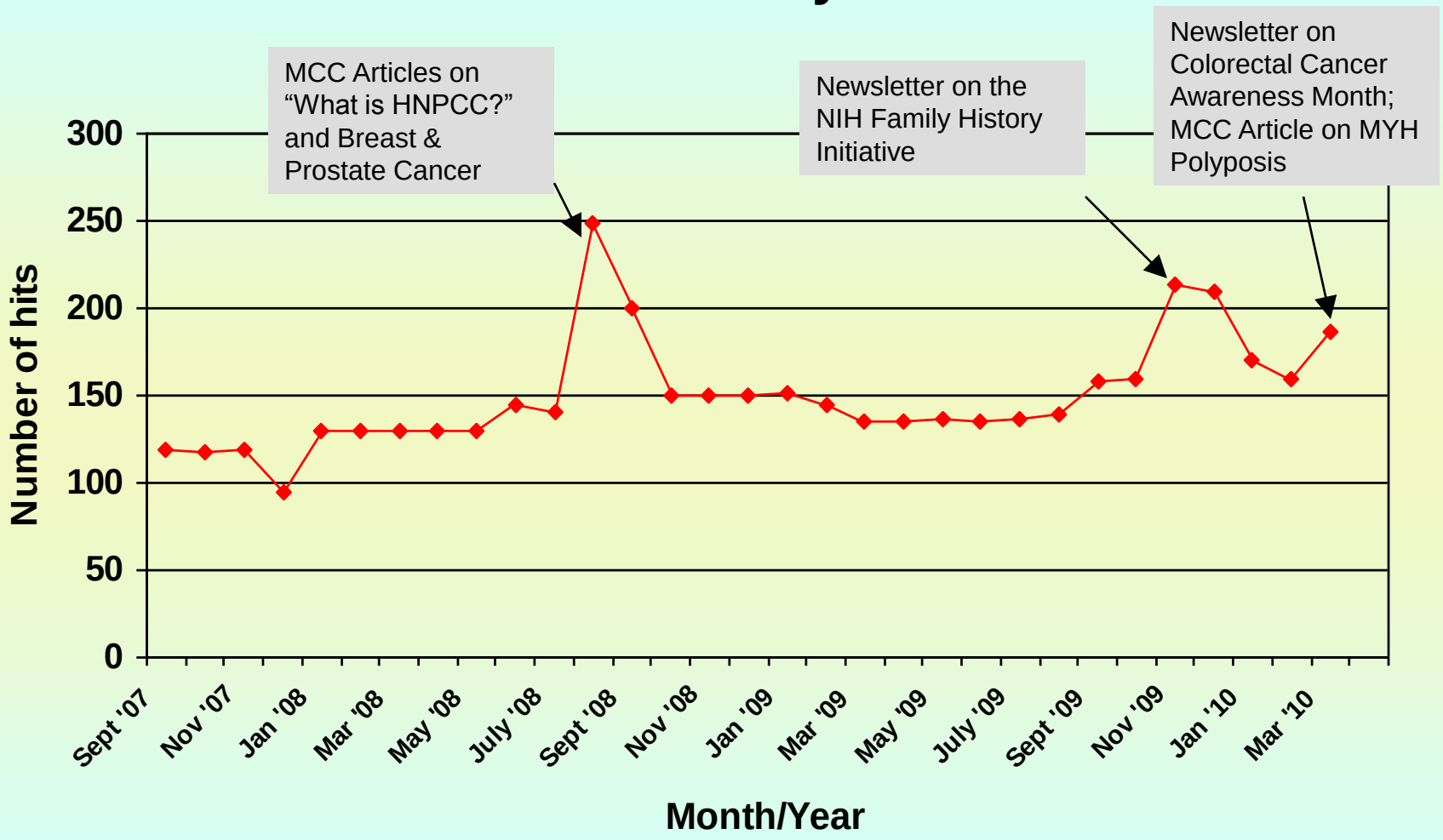
Impact of Gene Expression Profiling Tests on Breast Cancer Outcomes (2008)
http://www.ahrq.gov/downloads/pub/evidence/pdf/brcancergene/brcangene.pdf

Tumor Gene Expression Profiling in Women with Breast Cancer
http://knol.google.com/k/cecelia-bellcross/tumor-gene-expression-profiling-in/39jrm5yo7vhua/1?collectionId=1mzqt0rqcwdd.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

www.michigan.gov/genomics

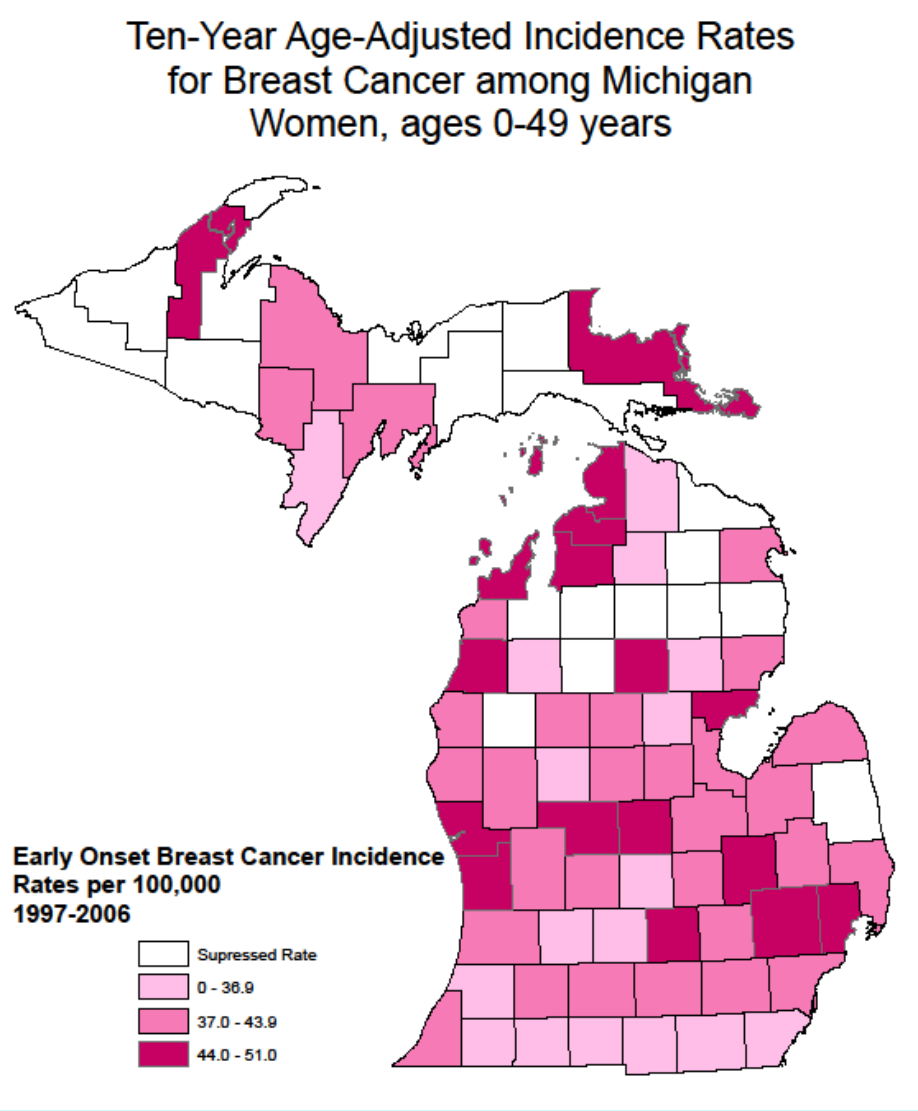
Cancer Services Directory Hits / Month



Beyond September 29, 2011

- Increase % of women with appropriate family history receiving BRCA counseling (HP2020)
  - Address barriers to BRCA counseling such as geography
  - Measure effects of new service delivery systems such as Informed Medical Decisions, Inc.
- Increase % of appropriate BRCA testing
  - Cascade screening starting with affected family member
- Increase % of colorectal cancer patients having Lynch syndrome screening (HP2020)
  - Expand clinical sites surveillance and health plan education to Lynch syndrome and other hereditary cancer syndromes (such as FAP, MYH)
- Disseminate AHRQ/RTI tool to relevant providers and systems
- Additional surveillance
  - Newer cancer registry elements (site specific factors, family history)
  - BRFS call-back survey to collect additional family history, genetic counseling and testing information
  - Hereditary Cancer Expert Mortality Review
  - Early Onset Breast Cancer Survivorship Survey
- Public education regarding Lynch syndrome
- Linkage of databases
  - Infertility to MCSP
  - BRCA positive from clinical sites to MCSP

Female Breast Cancer, 0-49 years



Source: Michigan Resident Cancer Incidence File

Infertility Project

- Michigan one of the three states to perform linkage of ART registry with live births, infant deaths, hospital discharge
- Pilot project for Michigan - linkage with cancer registry
  - *Infertility before and after cancer diagnostic and treatment*
- Potential research topics:
  - *Outcomes of ART Procedures for Patients Previously Treated for Cancer*
  - *Surveillance of cancer risk in women following ART*

Cancer – live births linkage update

- Preliminary results:
  - 36,924 women born between the years 1955 and 1988 had a birth link
  - The number of linked cases diagnosed before, within and following the linked birth year varied by cancer site:
    - Over 90% of breast and uterine cases followed the delivery
    - 64% of ovarian cancer cases followed the delivery
- Next steps:
  - Random cases selected for linkage validation
  - Link with ART through live births when IRB approval is obtain
  - Conduct epidemiological studies
  - Use the findings to develop strategies and policies as appropriate

Acknowledgements

Clinical Sites
Beaumont Hospital: Whitney Ducaine & Dr. Dana Zakalik
Henry Ford Health System: Katie Biro, Amy Decker & Dr. Jacquelyn Roberson
Karmanos Cancer Institute: Nancie Petrucelli *&* Dr. Michael Simon
Oakwood Hospital: Dr. Julie Zenger Hain

Health Plan "Champion"
Karen Lewis, *Priority Health*

Michigan Cancer Consortium (MCC)

Michigan Cancer Genetics Alliance (MCGA)
Kara Milliron, *Co-Chair*

Michigan Department of Community Health
Michigan Cancer Surveillance Program: Glenn Copeland, Won Silva, Michelle Hulbert & Jetty Alverson
Cancer Prevention and Control Section: Polly Hager & Ann Garvin

National Office of Public Health Genomics, CDC

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