

*Bidirectional Reporting of  
Michigan Cancer Registry  
Data to Increase Cancer  
Genetics Access*

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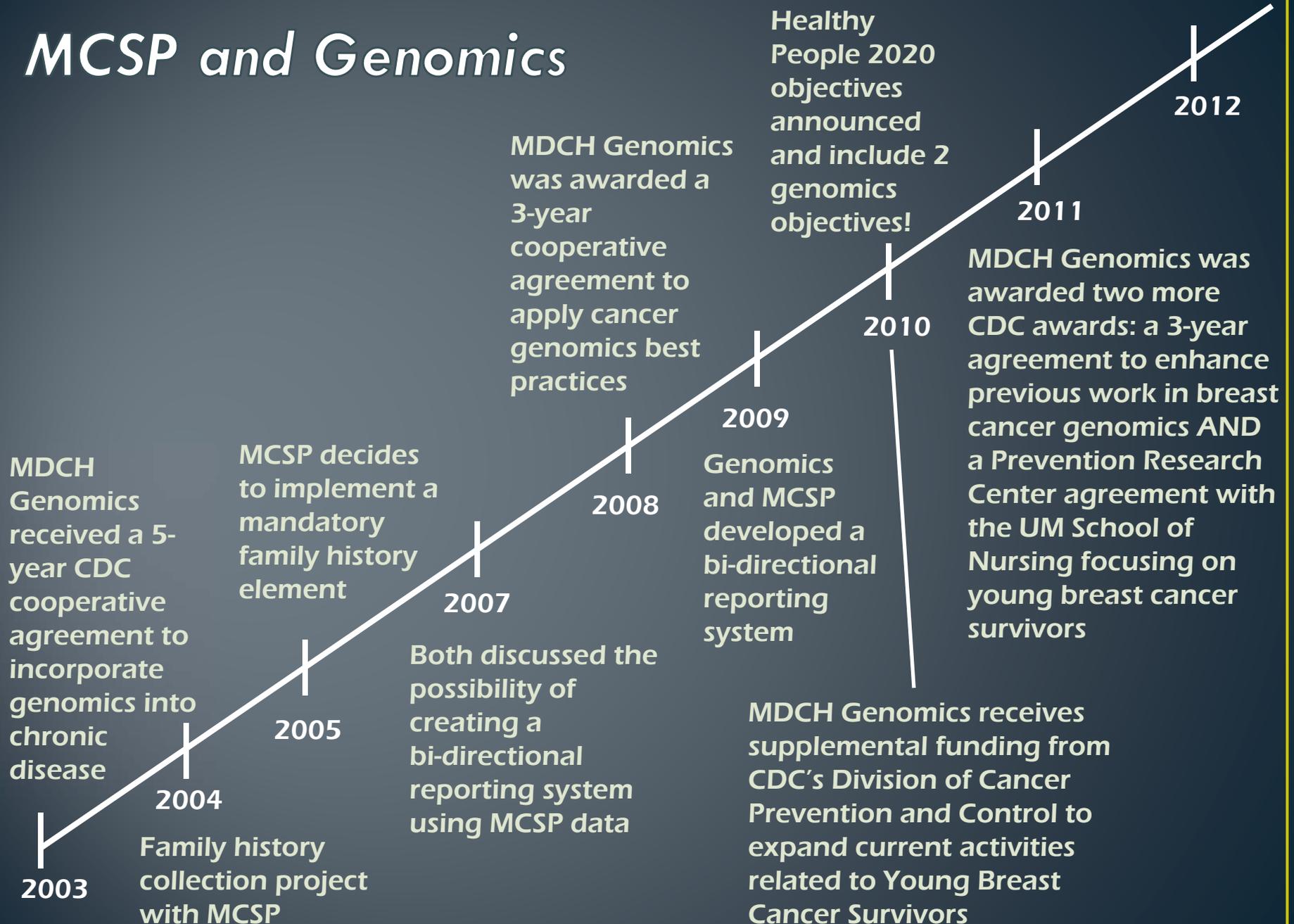
August 21, 2012

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

# Methods and Quality

- Michigan Cancer Surveillance Program
  - Established by law (Act 82 of 1984) – statewide reporting since 1985
    - Cancer and precancerous disease
  - NPCR Registry since 1995
  - NAACCR Certified since 1999
- Passive Reporting System
- Quality Assurance Reviews
- Benefits from large SEER registry encompassing 3 counties in the metro Detroit region

# MCSP and Genomics



# Registry Uses

- Data
  - Statistics on incidence and mortality
  - Cancer Control Outcome Measures
  - Facilitated over 112 research protocols
- Intervention Tool
  - Improved screening of family risk
  - Method of contacting cancer survivors
  - Family history chart reviews (2003-2004 – Chart review of 853 charts)
    - 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

## *Cooperative Agreement (2008-2011, extension into 2012)*

- Promote cancer-genomics best practices and evidence-based recommendations
  - U.S. Preventive Services Task Force Grade B Recommendation Statement for *BRCA* Genetic Counseling and Testing
  - EGAPP Recommendation Statement on Lynch Syndrome Genetic Testing
- Activities included surveillance, education, and health plan policy projects
- The project demonstrated the translation of surveillance data into education and practice

# Selection Methods

- Single Primary Cancers - number of cancer cases in 2006-2007
  - Any age: Colorectal (Lynch), Male Breast (BRCA), or Ovarian (BRCA & Lynch)
  - 18-49 years: Female Breast (BRCA), Endometrial (Lynch)
- Multiple Primaries - 1990-2007, with at least one diagnosis in 2006 or 2007
  - Defined as  $\geq 2$  BRCA1/2 or potentially Lynch-related cancers that were classified as separate primary tumors
  - i.e. breast-breast, breast-ovarian, colorectal (CRC)-endometrial, CRC-CRC

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## Sample Hospital and Medical Center Cancer Genetics Data Report (2006-2007)

on Hereditary Breast and Ovarian Cancer Syndrome (HBOC)  
 and Lynch Syndrome

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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.

	Sample 2006 - 2007	Michigan 2006 - 2007
Breast (female)		3,025
Endometrial		459

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

	Sample 2006 - 2007	Michigan 2006 - 2007
Colorectal		10,340
Ovarian*		1,544
Breast (male)		147

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

	Sample 2006 - 2007	Michigan 2006 - 2007
Multiple primary cancer diagnoses		1,985

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

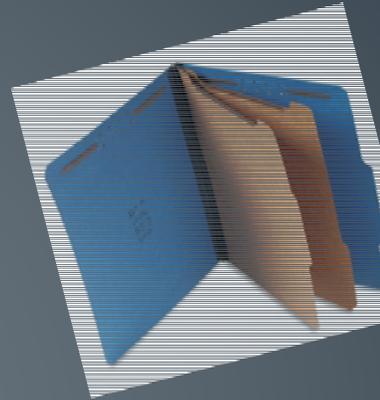
\* All ovarian cancer data also include those cases diagnosed with cancer of the fallopian tube. Patient names associated with the reported diagnoses can be sent to a designated person in your facility upon request. If requested, the names will be disclosed to your facility using current confidentiality rules.

Prepared in 2010 by MDCH staff

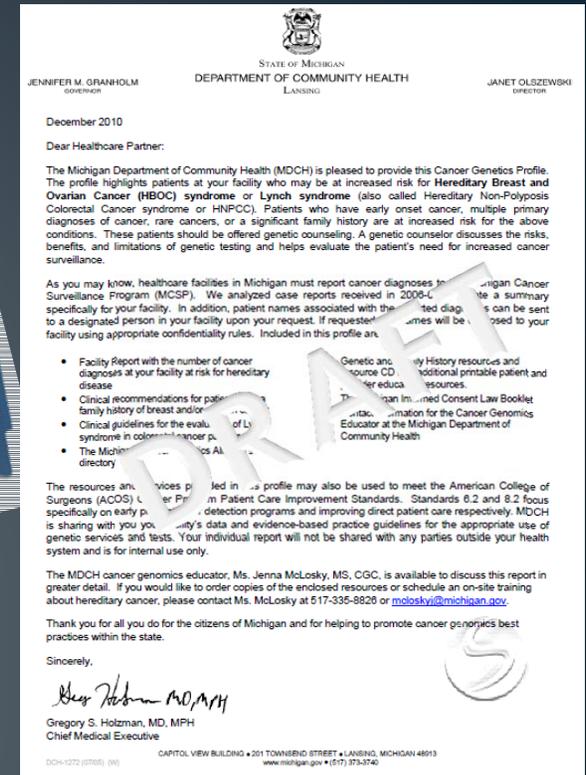
# Facility Specific Profiles

## TARGET AUDIENCE:

Cancer Registrar  
President and CEO  
Medical/Clinical  
Affairs  
Medical Director  
Quality Assurance/Risk  
Management  
Patient Care  
Legal Affairs  
Nursing  
Oncology  
OB/GYN  
Medical Education



- Introductory letter
- Guidelines
- Data Report
- MCGA Directory of Cancer Genetics Services
- Resources: MI informed consent brochure, newsletters, fact sheets
- Front cover: Resource CD, MDCH fact cards, and our new pocket guide

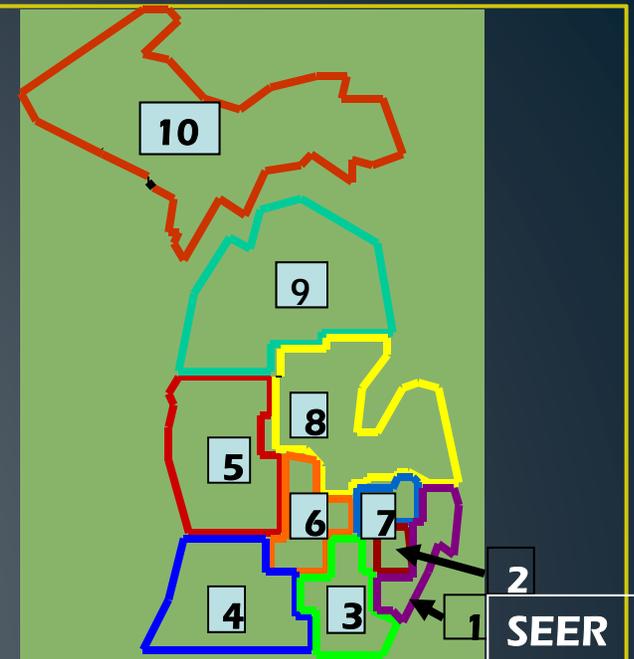


# Dissemination

- MCSP occurred by region
- 15 facilities no reported high risk cases
  - We went back to 2003-2007
  - Reports were generated for 10 additional sites; 5 received educational packets only
- Total dissemination for occurred to 112 /114 MCSP facilities (331 packets total)
  - 1 was held to be mailed with SEER sites
  - 1 facility's only report was returned sender

Overall  
Bidirectional  
Reporting  
Pilot →

151 Michigan  
Facilities  
434 Facility  
Profiles



SEER facilities identified and consented to share data

- 13 sites closed
- Reports were generated for 38/51 individual hospitals or clinic sites plus 1 from the MCSP sites (including 15 major Michigan health systems)
- 103 SEER packets sent in total

# Evaluation

- Follow-up contact was initiated with all 151 facilities by either email or phone call messages to registrar
- Received 11 Feedback Forms
- 9/11 very positive
- 7/11 reported sharing the report with others in and outside of their facility
- One facility is using the data as a baseline for their genetics program
- 8 facilities scheduled grand rounds specifically because of these packets
- 5 facilities requested the names of the individuals in their report so they can follow-up with the patients and provide educational materials or support

The Michigan Department of Community Health (MDCH) invites you to provide feedback on this Genetics Status Profile. Please return this brief survey in the prepaid envelope or visit <http://www.surveymonkey.com/s/cancergenomicsevaluation> to complete the survey online!

What county is your facility located in? \_\_\_\_\_

What is your current role at your facility?

- Cancer Registrar
- Administrator
- Physician
- Nurse Practitioner
- Legal Affairs or Risk Management Representative
- Other (please specify) \_\_\_\_\_

How did you access or receive this Facility-Specific Genetics Status Profile?

- I received a hard copy in the mail from MDCH
- I received an electronic copy from a colleague
- I received a hard copy from a colleague
- Other (please specify) \_\_\_\_\_

Overall, was the purpose of this profile clearly stated?

- Yes
- No
- Don't Know

Did you learn something new about cancer genomics in Michigan that you did not know before?

- Yes (if so, what? \_\_\_\_\_)
- No

Overall, this profile helped me understand the burden of cancer genomics in Michigan.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree
- Don't know

Overall, this profile helped me understand the burden of cancer genomics in my facility.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree
- Don't know

What part(s) of the profile did you find most useful? Please describe.

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What information was missing from this profile? Please describe.

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# Future Steps

- Dissemination of our state project as well as efforts from other states
  - Connecticut has been able to reproduce this project successfully in their state
- Current and Future Projects →
  - Cancer Registry Reporting Project to Michigan Providers
  - UM School of Nursing and Prevention Research Center: Recruiting Young Breast Cancer Survivors and High-Risk Relatives to a Randomized Trial using a State

# Acknowledgements

## MDCH Cancer Genomics Team

- Deb Duquette, MS, CGC – Adult Genomics Coordinator
- Beth Anderson, MPH – Cancer Genomics Epidemiologist
- Janice Bach, MS, CGC – State Genetics Coordinator and Manager

## Michigan Cancer Surveillance Program (MCSP)

- Glenn Copeland – Director, MCSP and Michigan Vital Records
- Georgia H. Spivak, BS - Statistician Specialist

## Surveillance, Epidemiology, and End Results (SEER) Program Epidemiology Section - Research Unit Metropolitan Detroit Cancer Surveillance System (MDCSS)

- Ronald D. Shore, MPH - Biostatistical Programmer
- Fawn Vigneau, JD, MPH - Co-Director, Epidemiology Research Core

## CDC Office of Public Health Genomics (OPHG)

## CDC Division of Cancer Prevention and Control (DCPC)