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

November 16, 2013

Angela Trepanier, MS, CGC
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

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

Wylie Burke, MD, PhD, Mumin J. Khouy, MD, PhD, Alison Stewart, PhD, and Ronald L. Zimmern, MA, FFPHM for the Bellagio Group

...
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.
Assurance: That genomic information is used appropriately and that genetic tests and services meet agreed upon goals for effectiveness, accessibility, and quality.
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
MDCH Cancer Genomics Program
Michigan’s Timeline

1990s
- BRCA 1/2 and Lynch Syndrome genetic testing moves into clinical practice
- Genetics Program “discovers” Comprehensive Cancer Control Program

2000
- MI Informed Consent Law for Genetic Testing Begins

2002
- Genetics staff participates in Michigan Cancer Consortium

2003
- Cancer Program participates in genetics needs assessment and state plan process
- Michigan Cancer registry (MCSP) family history chart reviews

2005
- “Cancer Genomics for Public Health” seminar series
- MCSP Mandatory family History fields for Reportable cancers

2007
- Cancer Genetics Clinic Network for Data Collection begins

2008
- Genomics goal and objectives in state cancer plan, 2009-2015
- CDC Cooperative Agreement: Genomics Applications in Practice and Prevention, 2008-2012
- Michigan Cancer registry (MCSP) family history chart reviews

2010
- CDC Cooperative Agreement: Genomics Integration in Public Health Programs, 2003-2008
- Work with Michigan health plans begins

2011
- LSSN formed

2012
- DCPC supplemental funding for young breast cancer survivors activities, 2010

2013
- CDC Prevention Research Center-Special Interest Project: Potential for Cancer Screening Interventions for Cancer Survivors Delivered Through Central Cancer Registries, 2011-2013

2011
- MI Informed Consent Law for Genetic Testing Begins
- MCSP Mandatory family History fields for Reportable cancers

2013
- CDC Prevention Research Center-Special Interest Project: Potential for Cancer Screening Interventions for Cancer Survivors Delivered Through Central Cancer Registries, 2011-2013
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

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

Download all Genomics Objectives [PDF – 10 KB]

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

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

Download all Genomics Objectives [PDF – 10 KB]

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“…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.”

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 BCA 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)

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

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

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
• Multi-faceted, state-wide comprehensive program
• Translation of evidence-based recommendations for genetic tests into practice
  o USPSTF BRCA recommendations
  o EGAPP recommendations on Lynch syndrome
  o EGAPP recommendation on breast cancer gene expression profiling
• Goals to:
  o 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
  o 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
  o 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

- 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

Michigan Cancer Consortium; FORCE

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

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

Michigan Cancer Genetics Alliance

Priority Health

15 Clinical Cancer Genetics Sites

NCHPEG; Wayne State; Emory

CDC Division of Cancer Prevention and Control

CDC Office of Public Health Genomics
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
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

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

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.

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

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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

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Rates are per 100,000 population and age-adjusted to the 2000 US Standard Population.
* Rates based on fewer than 20 cases are unstable.
A Cancer Genetics Profile: Prepared for Sample

Focusing on Your Patients’ Hereditary Cancer Risk
March 1, 2010

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

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Breast (female)</td>
<td>199</td>
</tr>
<tr>
<td>Endometrial</td>
<td>30</td>
</tr>
</tbody>
</table>

Table 2. Number of colorectal, ovarian* cancer and multi-breed diagnoses within your health system and within Michigan.

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Colorectal</td>
<td>476</td>
</tr>
<tr>
<td>Ovarian*</td>
<td>127</td>
</tr>
<tr>
<td>Breast (male)</td>
<td>12</td>
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Table 3. Number of people with multiple cancer diagnoses between 1990 to 2007 with a cancer diagnosis in 2006-2007 including breast, breast-ovarian, ovarian-ovarian, colorectal, colorectal-ovarian, colorectal-endometrial, ovarian-endometrial.

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Multiple primary cancer diagnoses</td>
<td>106</td>
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</table>

* 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.
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 Primaries 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

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 Genetics, Education Coordinator
Michigan Department of Community Health

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

Your patient is a 30-year-old, African American female seen in clinic for her annual checkup. 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 none.

How do you proceed?

1. Her risk for hereditary cancer syndrome 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 study does not seem clear cut. After thorough discussion and informed consent, you order the patient's blood for genetic testing (BRCA1/2).
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.
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 give at 21 hospitals
      - 70% of hospitals reached
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

Anderson B et al. J Cancer Epidemiology, 2012
Michigan YBCS Survey Results

- 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

Anderson B et al. J Cancer Epidemiology, 2012
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%)

<table>
<thead>
<tr>
<th>Table 9. Barriers to Receiving Genetic Services Among YBCS</th>
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<tbody>
<tr>
<td>n=158 (54.7%)</td>
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<tr>
<td>No one ever recommended it</td>
</tr>
<tr>
<td>Medical insurance coverage issues</td>
</tr>
<tr>
<td>Did not know they existed</td>
</tr>
<tr>
<td>Worried a genetic test could be used against me</td>
</tr>
<tr>
<td>Too nervous</td>
</tr>
<tr>
<td>A doctor told me not to go</td>
</tr>
<tr>
<td>Lack of transportation</td>
</tr>
<tr>
<td>Other life arise that are more important</td>
</tr>
<tr>
<td>Too busy</td>
</tr>
<tr>
<td>Disability makes it difficult to carry out daily activities</td>
</tr>
<tr>
<td>Family members wouldn’t want me to go</td>
</tr>
</tbody>
</table>

Anderson B et al. J Cancer Epidemiology, 2012
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.

Katapodi et al. BMC Cancer, 2013
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

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

“…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…..”

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

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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!

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