

# **CDC Research and Programmatic Activities in Breast Cancer Genomics**

**Advisory Committee on Breast Cancer in Young Women Meeting  
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**Enhancing Breast Cancer Genomic Practices  
Through Education, Surveillance, and Policy  
PROGRAMMATIC ACTIVITIES**

## **Background**

- ❑ **Since 2003, the Office of Public Health Genomics (OPHG) at CDC has been working with state health departments to integrate genomics knowledge and tools into state chronic disease prevention programs and core public health functions**
- ❑ **In 2010 through the existing OPHG cooperative agreements, DCPC provided additional funds to two states to expand their activities in breast cancer genomics**

## 2010 Program Activities

- ❑ **The Michigan Department of Community Health was provided funding to:**
  - Expand surveillance of genetic counseling and BRCA 1/2 genetic testing
  - Explore the feasibility of linking BRCA positive patients with state cancer registry data
  - Expand identification of state health insurance plans and evaluate medical policies for coverage of genetic counseling and testing, and related preventive services
  - Increase dissemination to health insurance carriers of appropriate medical policy for genetic counseling and testing, and related preventive services

## Michigan Accomplishments: Surveillance

- ❑ **Expanded *BRCA* clinical network database to capture data from all board-certified cancer genetics clinics**
  - 4 in 2009, 14 in 2012
- ❑ **Pilot study of 200 cases from cancer registry in need of *BRCA* counseling**
  - Targeted information sent to provider, link with local genetics providers
- ❑ **Surveyed women from 8 cancer genetics clinics with known *BRCA* mutation or true negatives**
  - Impact of test results on health decisions

# Michigan Accomplishments: Policy and Education

- ❑ **Increase identification and review of health plans for coverage**
  - 24 in 2009 to 26 in 2012
  - 12 plans recognized as being aligned with USPSTF recommendations
- ❑ **Increased dissemination of physician education tools**
  - 13,000+ Cancer Family History Guides distributed
  - Assist providers in identifying high-risk patients for referral to genetics specialist

## 2010 Program Activities

- ❑ **The Oregon Department of Human Services was provided funding to:**
  - Expand surveillance of genetic counseling and BRCA1/2 genetic testing
  - Expand identification of state health insurance plans and evaluate medical policies for coverage of genetic counseling and testing, and related preventive services
  - Expand collection and analysis of Medicaid data on BRCA testing and follow-up procedures
  - Add questions on family history and genetic testing to the Oregon BRFSS
  - Collaborate with the state screening program to develop a conceptual model for educating and identifying high risk clients.

## **Oregon Accomplishments: Surveillance**

- ❑ **Analyzed Oregon State Cancer Registry data to estimate burden of cancers with genetic component**
- ❑ **Analyzed genetic service provider data to estimate use of cancer genetic services**
  - BRCA carrier prevalence estimate between 17,000-24,000
  - 1421 sought genetic services for hereditary breast/ovarian cancer
    - Only a small fraction of who should be seen are being seen
- ❑ **Analyzed Oregon Medicaid data for BRCA testing**
  - Medicaid covers USPSTF and NCCN recommended services
  - Increase in coverage: 0 tests paid for in 2007 to at least 52 in 2009
  - Still lower than ideal
    - ~ 3,600 Medicaid-covered women may be eligible for genetic services

# **Oregon Accomplishments: Education and Policy**

- ❑ **Surveyed third party payers' policies for genetic counseling, testing, and follow-up procedures**
  - All insurers covered some genetic testing for those with cancer, 9/10 covered some for those with just a family history
  - Most covered increased breast cancer screening for positive patients, coverage for mastectomy, oophorectomy, chemopreventive drugs were less consistent
- ❑ **Analyzed data from a health care provider survey on cancer genetic testing**
  - Quantify knowledge and disparities in access
  - <30% of primary care physicians use family history information to determine referral to genetic services
  - Primary care physicians are least confident in their cancer genetic knowledge (vs. ob/gyns and cancer specialists)

## **Program Activities: New FOA**

- ❑ **In 2011, the Division of Cancer Prevention and Control released a new funding opportunity to continue and expand activities started through the OPHG cooperative agreements**
- ❑ **New FOA: “Enhancing Breast Cancer Genomic Practices Through Education, Surveillance, and Policy”**
- ❑ **Posted June 8, 2011; closed July 25, 2011**
- ❑ **Competitive process, objectively reviewed**
- ❑ **Funded 3 applicants, at approx. \$300,000 per year, for 3 years**
  - **Georgia, Michigan, Oregon**

## Limited Eligibility

- ❑ **State and local governments or tribal organizations were eligible to apply**
- ❑ **Develop, expand work already underway at state level**
- ❑ **Likely to have necessary expertise in surveillance, policy and education**
- ❑ **Ability to work with state partners, influence state policies**
  - Connection with cancer registry, health insurance providers (differences at state level)
- ❑ **Model for national approaches?**

## **Program Activities: New FOA**

- ❑ **Programs funded under the new cooperative agreement are working in the following areas:**
- ❑ **Policy**
  - E.g., Use policy interventions to promote the increased use of clinical best practices for genetic counseling, BRCA1/2 testing, and preventive services for those identified as high risk
- ❑ **Education**
  - E.g., Develop or expand public and provider education to increase knowledge on the importance of family history, appropriate risk assessment and communication, genetic counseling and BRCA1/2 testing, and preventive services for those identified as high risk

# Program Activities: New FOA

## ❑ Surveillance

- Track the use of genetic counseling and BRCA1/2 testing, follow-up procedures for those identified as high risk, and family medical history tools or family medical history based risk assessment tools for breast and ovarian cancer

## ❑ Applicants required to propose activities in 2 of 3 areas

- One of which had to be policy
- All awardees addressing all 3

## **Georgia Proposed Activities**

- ❑ **Education: Increase knowledge and awareness of methods and benefits of identifying women at risk for hereditary breast/ovarian cancer among clinicians, public health practitioners, insurers and young women**
- ❑ **Surveillance: Assess the utilization of and barriers to cancer genetic services**
- ❑ **Policy: Expand coverage for cancer genetic services for high risk women**

# Georgia Accomplishments to Date

- ❑ **Education: Increase knowledge of methods and benefits of identifying women at risk**
  - Identify knowledge gaps through provider survey
  - Facilitate integration of genetic risk screening protocols into existing Breast and Cervical Cancer Prevention Programs (BCCP)
- ❑ **Surveillance: Assess utilization of and barriers to cancer genetic services**
  - Develop network of genetic counselors to ascertain baseline and post-implementation data
  - Implement Breast/Ovarian Cancer Genetics Referral Screening Tool (B-RST) to improve the identification of women at high risk
- ❑ **Policy: Expand coverage for cancer genetic services for high risk women**
  - Promote coverage of cancer genetic services through partnerships

## Michigan Proposed Activities

- ❑ **Expand surveillance of genetic counseling and *BRCA* 1/2 genetic testing**
- ❑ **Explore the feasibility of linking *BRCA* positive patients with state cancer registry data**
- ❑ **Expand identification of state health insurance plans and evaluate medical policies for coverage of genetic counseling and testing, and related preventive services**
  - USPSTF and NCCN
- ❑ **Increase dissemination to health insurance carriers of appropriate medical policy for genetic counseling and testing, and related preventive services**

## **Michigan Accomplishments to Date**

- ❑ **In 2012, 9 health plans' written policies on *BRCA*-related clinical services for women with a known deleterious *BRCA* mutation have been reviewed, and all are consistent with 2011 NCCN guidelines**
- ❑ **In 2012, MDCH began working with the Cancer Resource Foundation, Inc. to pilot a novel co-pay program for appropriate cancer genetic testing as deemed by NCCN guidelines for underinsured Michigan residents (<http://cancer1source.org/>)**
- ❑ **Many presentations and publications**

## **Oregon Proposed Activities**

- ❑ Implementing a BRCA surveillance system**
- ❑ Promoting insurance coverage for genetic counseling and genetic testing for women at increased risk**
- ❑ Promoting legislation of licensure for certified genetic counselors**
- ❑ Educating health professionals and the public on the appropriate use of genetic services**
- ❑ Educating Ashkenazi Jewish population**

# Oregon Accomplishments to Date

- ❑ **BRCA surveillance system**
  - Covers all 5 genetics clinics, 1 oncology clinic
  - Contracts to provide data are in place for most clinics
- ❑ **Promoting insurance coverage**
  - Medicaid and private insurers
- ❑ **Promoting licensure for certified genetic counselors**
  - Building partnerships and support through education
- ❑ **Educating health professionals and the public**
  - Set up a regular call with providers in the Oregon Breast and Cervical Cancer Early Detection Program
  - Provider resource page
- ❑ **Educating Ashkenazi Jewish population**
  - Partnering with non-profits to provide educational outreach (e.g. community presentations, social networking)
  - Creation of a tool kit of materials (family history tracking tool, resources)

**Health Insurance Coverage of Genetic and  
Prevention Services in Populations at  
Increased Risk for Breast and Ovarian Cancer  
RESEARCH**

# **Health Insurance Coverage for Genetic Counseling & Testing, and Related Clinical Services**

- ❑ It is unclear what breast and ovarian cancer genetic services are covered by health insurance plans and the requirements for coverage**
- ❑ Also, it is unknown what guidelines or evidence is used to develop medical policy**
- ❑ DCPC conducting a review of health insurance medical policies for BRCA 1/2 genetic counseling and testing**
  - Also coverage of clinical preventive services reviewed**

## **Research Questions**

- ❑ What are the conditions or stipulations for coverage of genetic counseling and testing for hereditary breast and ovarian cancer ?**
- ❑ What are the conditions for coverage of clinical preventive services for those individuals identified as higher risk?**
- ❑ What evidence is being used to justify medical policy?**
- ❑ Is there geographic variability in medical policy and coverage?**

# Methodology

- ❑ **Review being conducted at state level**
- ❑ **Within each state, a list of health insurance companies offering health insurance coverage is compiled**
- ❑ **Criteria for inclusion into review:**
  - Company must offer comprehensive group, family, or individual health insurance coverage
  - Number of covered lives within each company must be 1% or more of the market share
- ❑ **Public plans are automatically included in the review**
  - Medicare and Medicaid

# Methodology

- ❑ **Once plans selected, the health plan's website is searched for their relevant medical policies**
  - Search engines also used to retrieve relevant websites and documents
- ❑ **Retrieved health plan medical policies are then reviewed and abstracted into the study database.**
- ❑ **Original study methodology called for contacting health insurance companies where we had incomplete data, but this was suspended early in the study**

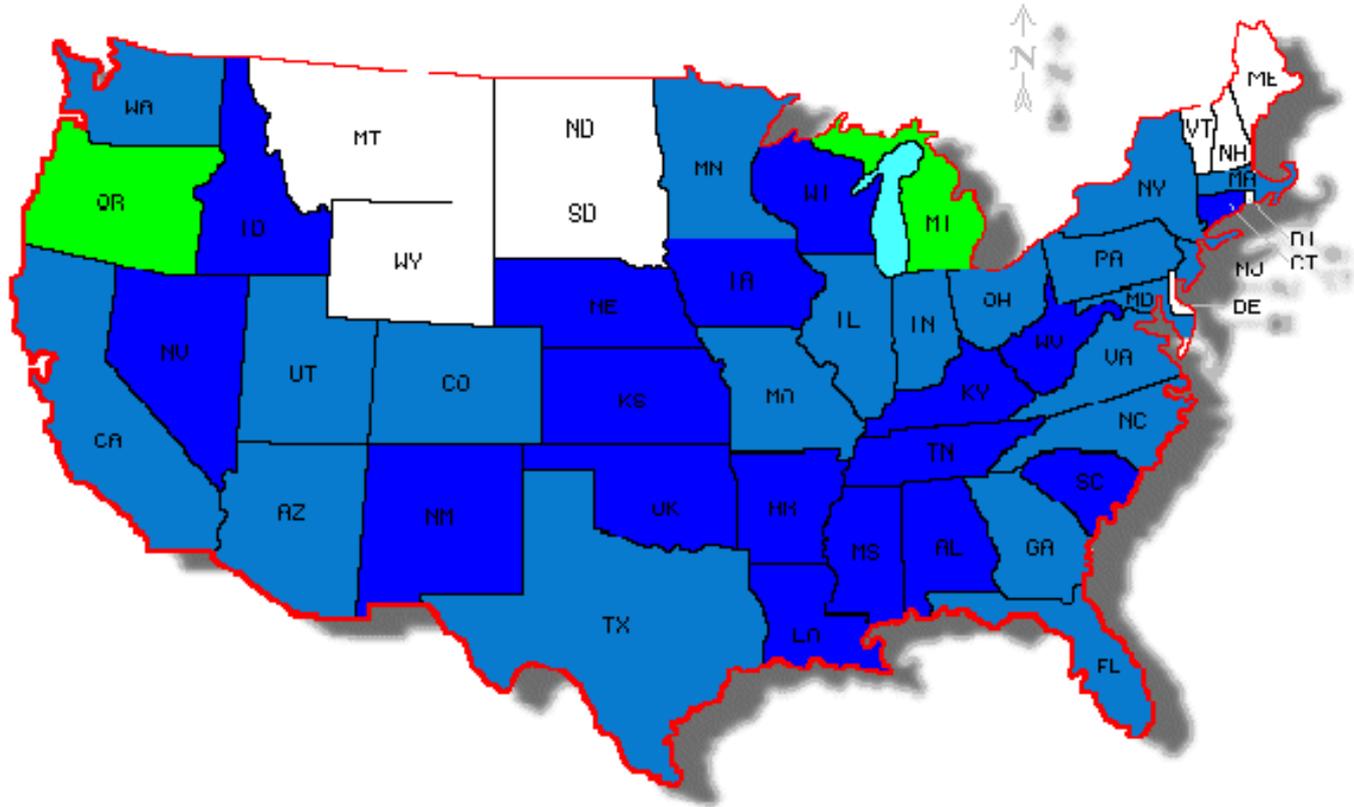
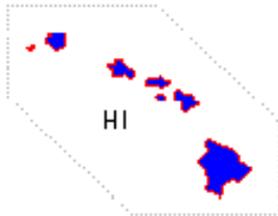
# Methodology

- ❑ **Medical Policies were reviewed for the following clinical services:**
  - Genetic counseling for breast and ovarian cancer susceptibility
  - Genetic testing for BRCA1/BRCA2 (BRACAnalysis)
    - BART Rearrangement Test
  - Prophylactic mastectomy and breast reconstruction
  - Prophylactic oophorectomy
  - Cancer Screening:
    - Mammography
    - Breast MRI
    - Breast Ultrasound
    - CA-125
    - Transvaginal Ultrasound
  - Chemopreventive Drugs

## **Preliminary Results**

- ❑ **Between September 2010 and February 2012, have reviewed medical policies for more than 200 health insurance companies in 38 states**
- ❑ **Have seen significant variability in requirements, or conditions, for coverage**
- ❑ **Several health insurance companies are using USPSTF guidelines as the basis for their medical policies**
  - Some going beyond USPSTF
- ❑ **Many health insurance companies lack detailed and comprehensive medical policies for these services**

# States Completed



## **Next Steps**

- Currently analyzing data; plan to present at CDC Cancer Conference in August**
- Work with state health departments and comprehensive cancer control programs to improve the medical policies of health insurance carriers in their respective states**
- Have significant work to do at the national level to deal with medical policies and insurance coverage, medical billing, lack of capacity, and issues related to access**

# Any Questions?

# Thank You!

**For more information please contact Centers for Disease Control and Prevention:**

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