Cancer Genomics Surveillance: Are Oregonians Receiving Appropriate Cancer Genomics Testing?

A Preliminary Analysis

Nanette Newell, Ph.D., MBA

November 10, 2010

APHA

Oregon Health Authority

Presenter Disclosure
Nanette Newell

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

“No relationships to disclose”

What is cancer genomics….

- All cancers are a result of at least one mutation.
- For most cancers, the mutation(s) are acquired during a lifetime.
- Some cancers originate with mutations that are inherited.
- Cancer genomics is the study of the molecular basis of cancer, both inherited and acquired
  - Genomics = genetic + environmental factors + their interactions

and why should you care?

- Cancers with known heritable mutations often are found in people younger than those with acquired mutations & carriers are more likely to develop a 2nd primary cancer.
- Most public health cancer screening programs are directed at “average risk” populations.
- People with a strong hereditary risk of cancer need to be identified as “high risk” and screened accordingly
- Identification of high risk populations affects many facets of public health:
  - Surveillance
  - Education
  - Policy

Overarching Program Goal

Develop, implement, and evaluate a surveillance program to monitor the use of cancer-specific evidence-based genomic tests and family history in Oregon.

Surveillance Objective (1 of 4)

Evaluate disparities in Oregonians' access to genetic testing & genetic counseling for colorectal, breast, & ovarian cancer

Hereditary Cancer Mutations

- BRCA and MMR are the focus of this study
- Autosomal dominant mutations (50% chance of inheriting mutation)
- Accurate genetic tests available
- Evidenced-based medical care for pre-symptomatic mutation carriers
- Economically worthwhile to identify individuals and family members with a mutation

BRCA Mutations

- Associated with breast and ovarian cancer (BOC)
- Lifetime risk for women: 50-85% for BC; 15-45% for OC (12% and 2% average risk)
- Average age of onset 15 years earlier than average risk women
- 2-3% of those with BOC have BRCA mutations

MMR Mutations

- Associated with colorectal and endometrial cancer (CRC / EC)
- Lifetime risk: 70% (6% and 3% for average risk)
- Average age of onset 15 (EC) - 25 (CRC) years earlier than average risk population
- 2.3-3% of those with CRC and EC have MMR mutations

Disparities - Questions & Data Sources

How many Oregonians should be getting cancer genetic counseling and testing?

~~How many Oregonians~~ are getting appropriate cancer genetic counseling and testing?

Genetic services clinical data: 7 clinics seeing ~1700 adult patients (2007-2008)

Medicaid database: ~157,000 enrolled adults

Interviews of **3rd party payers**: top 10 insurers cover 1.7 million lives

Surveys of **health care providers**: ~2500 1˚ care and cancer specialty providers

Behavioral Risk Factor Surveillance Survey (random telephone survey): 1,800 respondents representing 2.9 million adults, 2008-11

Cancer Registry Data: ~85,000 relevant cancers in 2.9 million adults in 12 years (1996-2007)

Hereditary Cancer Burden in Oregon

- Estimated carrier prevalence in 2007
  - ~17,000-24,000 BRCA mutation carriers
  - ~1,700-5,600 MMR mutation carriers
- Estimated # diagnosed with cancer per year who are likely to have a BRCA or MMR mutation
  - ~800-1150 women for BRCA
  - ~400-550 for MMR

Oregon Cancer Registry

- For some cancers, Oregon cancer incidence rates are significantly different than national rates
- Cancer incidence rates do not vary significantly among Oregon counties
- Race/ethnicity – Cancer incidence numbers are too small to assess statistically for all but White (90%)

Genetic Clinic Data – 2007-2008

- 1,716 patients were seen for BOC, CRC, and EC in 6 cancer genetics clinics in Oregon.
- Of ~ 600 patients seen in 2008,
  - 313 were tested for BRCA
  - 21 were tested for MMR
- Compared to the estimated carriers in the population, only a small proportion of Oregonians who may benefit from genetic counseling and genetic testing are being seen in Oregon cancer genetics clinics.

Medicaid Data - 2007

- Oregon guidelines for coverage of cancer genetic testing were implemented in 2007.
- Oregon Medicaid paid for 1,734 adult genetic tests. At most, 9 were for BRCA or MMR tests.
- Genetic testing for BOC and CRC appears to have been underutilized in Oregon's Medicaid population in 2007.

Public Knowledge of Colorectal Cancer (2008 BRFSS)

Public's awareness of family history (FHx) of CRC can mitigate risk for developing CRC.

- People with a FHx were 2x more likely to have CRC screening.
- Oregonians' recall of clinician's behavior – patient's FHx of CRC motivates clinicians to:
  - counsel patients with a positive FHx about their risk for the disease
  - encourage strategies to decrease that risk, e.g., appropriate screening & lifestyle changes
- Oregonians with a FHx have increased perceived risk of disease and reported making lifestyle changes

Health Care Provider Practices - Oregon Cancer Genetics Survey

- Target groups:
  - Primary care (family medicine, internists, PAs, NPs)
  - Naturopaths
  - OB/GYN
  - Oncology and surgery
- Administered to 2506
- 2259 are considered eligible
- Response rate to date 47%
- Target groups responding equally

Assessing Disparities to Date

- Only a small proportion of Oregonians who may benefit from genetic services are being seen in cancer genetics clinics
- Oregon has only 5 cancer genetics clinics: 4 in Portland and 1 in Eugene
- ~20% of Oregonians live more than 80 miles from a clinic
- <5% of those seen in cancer genetic service clinics are uninsured or Medicaid patients
- BOC is much more recognized by practitioners for its hereditary components than is CRC/EC

Many Thanks to:

- Amy Zlot, Kerry Silvey, Bob Nystrom – Oregon Genetics Program
- Dr. Nicoleta Voian – OHSU medical genetics resident
- Donald Shipley and Cathy Riddell – Oregon Cancer Registry
- PSU Survey Research Lab
- Amy Flowers – Analytical Insight
- Funded through CDC Cooperative Agreement # CDC-RFAGD08- 801 (grant # 1U38GD000061)

Oregon Health Authority

Surveillance Project Objectives

- Evaluate how familial risk of colorectal, breast & ovarian cancer influences Oregon healthcare practice & Oregonians' behavior
- Evaluate Oregonians' awareness, knowledge, & use of BRCA 1 & 2 testing
- Evaluate Oregon healthcare providers' knowledge, attitudes, & use of genetic tests for colorectal, breast, & ovarian cancer
- Evaluate disparities in Oregonians' access to genetic testing & genetic counseling for colorectal, breast, & ovarian cancer

Methodology / Data Sources

- Oregon State Cancer Registry
  - Cancers and proxies for cancers with a strong hereditary component (early-onset, multiple primary, & males with breast cancer). Use for denominators for age, race/ethnicity, and geographical distribution.
- BRFSS
  - Family history, lifestyle changes, screening behavior, genetic testing and counseling for hereditary BOC & CRC, HCP screening, behavior change recommendations
- Survey of HCPs (primary and specialty care)
  - Knowledge, use, attitudes, disparities, demographics

Methodology / Data Sources (cont.)

- Genetic services clinical data
  - Data from all 7 genetics centers that see patients for cancer reasons : # of pts referred, # of tests deemed appropriate and done, diagnoses, age, geographic location & follow-up information
- Medicaid encounter data
  - # tests done on cancer patients, compliance with guidelines, age, geographic location, disparities
- Private health insurer policy interviews
  - Compliance with guidelines, # lives covered, disparities