Oregon Cancer Genomics Surveillance Project

CDC Reverse Site Visit

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Overarching Project Goal

To develop, implement, and evaluate a surveillance program to monitor the use of cancer-specific evidence-based genomic tests and family history in Oregon.
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
Establish **Surveillance** Systems

**Family history:**
- How is family history used to identify people at high risk for colorectal, breast, ovarian cancer?
- Does understanding family history risk motivate people to change their behavior and lifestyle?

**Provider genetic testing:**
- BRCA 1 & 2 - Counseling, testing, follow-up, and medical procedures
- 9 cancer genomic tests - Knowledge, attitudes, and use by clinical practitioners
Surveillance, con’t

- Public and Private Health Insurance Coverage:
  - Collection and analysis of data on coverage of cancer genomic testing, counseling, and follow-up procedures
  - Comparison to practice guidelines
  - Expansion of original cooperative agreement
    - Follow-up procedures
    - More insurers
    - Compliance with Patient Protection and Affordable Care Act and USPSTF guidelines
Methodology / Data Sources

• Cancer Registry
  – Denominators for incidence, age and geographical distribution, disparities, proxies for cancers with a strong hereditary component

• BRFSS
  – Family history, lifestyle changes, BRCA and other genetic knowledge, HCP screening behavior

• Survey of HCPs (primary and specialty care)
  – Knowledge, use, attitudes, disparities, insurance status

• Genetic services clinical data
  – # of pts referred, # of tests recommended and done, diagnoses, age, geographic location

• Medicaid encounter data
  – # pts with diagnoses, # tests done, compliance with guidelines, age, geographic location, disparities

• Private health insurer policy interviews
  – Compliance with guidelines, # lives covered, disparities
Accomplishments to Date

• BRFSS
  – 2008 data analysis on CRC
  – 2009 BOC results expected end of summer
  – 2010 CRC questions in the field

• Oregon Cancer Registry 1996-2007 data

• Genetic Services Providers – complete data from 5 of 7 clinics

• Medicaid encounter data – preliminary data

• Surveys of HCPs – survey instrument completed, pilot and sampling plan by end of May

• Outside evaluation – Year 1 and Q1 Year 2 completed
Impacts to Date

• Measurable outcomes –
  – Several presentations and trainings
  – 2008 BRFSS data analysis
  – Cancer Registry data
  – Project revisions to increase relevance and supplemental funding

• Estimate of lives saved – ??
  – Trainings
  – Increase ID of high risk individuals
  – Change health behaviors
Plans for Next 1.5 Years
Anticipated Impacts after 3 Years

- Knowledge of how Oregon HCPs use family history and genetic tests – Appropriate use? Tailored education programs?
Disseminate Results to Partners and Public

- Articles submitted to peer-reviewed journals
- Presentations and trainings to collaborators and others
- Establish education programs for the public, health care providers
- Publish Oregon third party health care provider report card
Promote Policy Options

• Promote the **systematic use of practice guidelines** for:
  – reimbursement for genetic services by private and public third party payers
  – health care practitioners and systems

• Promote **equal geographic access** to genomic services by improving telemedicine and location of providers
Educate the Public and Health Care Providers

- **Public:**
  - How genomics influences health
  - Family history and reducing risk
  - Empower people to make informed decisions about genomics and their health
  - Use appropriate approaches for different racial/ethnic groups
Education, con’t.

- Develop partnerships with state health professional organizations and advocacy groups in order to educate Oregon health care providers about:
  - Clinical relevance of genomic medicine to primary and specialty care
  - Risk assessment (family history and other types of screening)
  - Diagnosis (use of genomic testing)
  - Treatment of genomic conditions (including motivating people at increased risk to make behavior changes to decrease their risks)
Beyond September 2011
Anticipated Impacts 5-10 Years

• Genomic testing & family history education program for HCPs implemented
• Evaluation of the outcomes and effectiveness of intervention in the early detection and prevention of genomic disease and susceptibilities related to genomic disorders.
• Personalized health screening and prevention programs for people at increased risk for colorectal, breast, & ovarian cancer
Anticipated Impacts 5-10 Years

- Personalized treatment for colorectal, breast, & ovarian cancer
- Population Health Impacts for Colorectal, Breast, & Ovarian Cancer
  - Decreased incidence
  - Decreased morbidity
  - Decreased mortality
  - Improved quality of life
  - Increased years of healthy life
Next slides are only for reference if needed
Nine Cancer Genetic Tests

- Population screening
  - Fecal DNA (CRC)
  - Multigene panels, e.g., OncoVue (BC)

- Testing populations at high risk
  - Mismatch repair gene mutation for HNPCC (CRC)
  - BRCA 1&2 (BOC)

- Treatment/management
  - BOC
    - BRCA 1&2
    - CYP2D6
    - Gene expression profiling (e.g., Oncotype DX)
  - CRC
    - MMR gene mutation
    - UGT1A1
    - BRAF
    - KRAS
Test Recommendations

• United States Preventative Services Task Force (USPSTF)
  – Fecal DNA
  – BRCA 1&2

• EGAPP
  – UGT1A1
  – MMR
  – Gene expression profiling (e.g., Oncotype DX)

• Under review
  – CYP2D6
  – BC screening panel
Challenges

• We are conducting a complex surveillance program on tests with variably-proven validity & utility.

• Although partners are supportive & see the value of our program, providing data to us is not their highest priority.

• We need to survey ~4500 physicians (or several representative samples) on complex topics.

• We need genetic testing data that cannot be obtained with the CPT codes for genetic testing.

• The prevalence of genetic mutations which predispose our population to cancer is unknown (# of Oregonians in denominator).
Key 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?

Medicaid database: ~157,000 enrolled adults

Behavioral Risk Factor Surveillance Survey (random telephone survey): 2000 people representing 2.9 million adults

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

Genetic services clinical data: 7 clinics seeing ~1300 adult patients in 2 years

Surveys of health care providers: ~4500 1° care and cancer specialty providers

Cancer Registry Data: ~85,000 relevant cancers in 2.9 million adults in 10 years
Assessing Disparities

- Insured & uninsured
- Types of insured: Medicaid, HMO, other
- Safety net clinics
- Rural & urban
Conclusions

• At 11 months into the grant, we are satisfied with our progress.
• We are constrained by the time availability of our partners.
• Anecdotal conversations suggest that primary care providers do not have time to adequately conduct cancer genetic risk assessment & therefore other assessment mechanisms or approaches to primary care assessment may be necessary.
• Our surveillance program is on track to contribute to GAPPNet’s genomics mission.