Oregon Cancer Genomics Surveillance Project

CDC Reverse Site Visit

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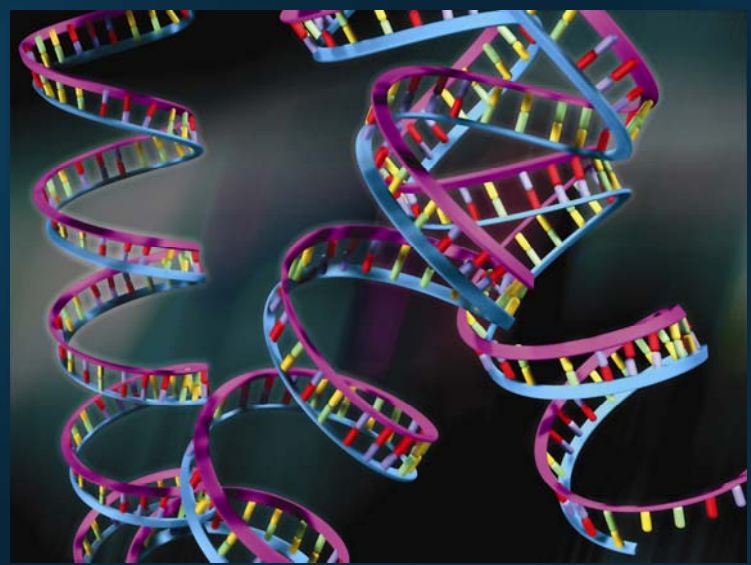
Overarching Project Goal

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

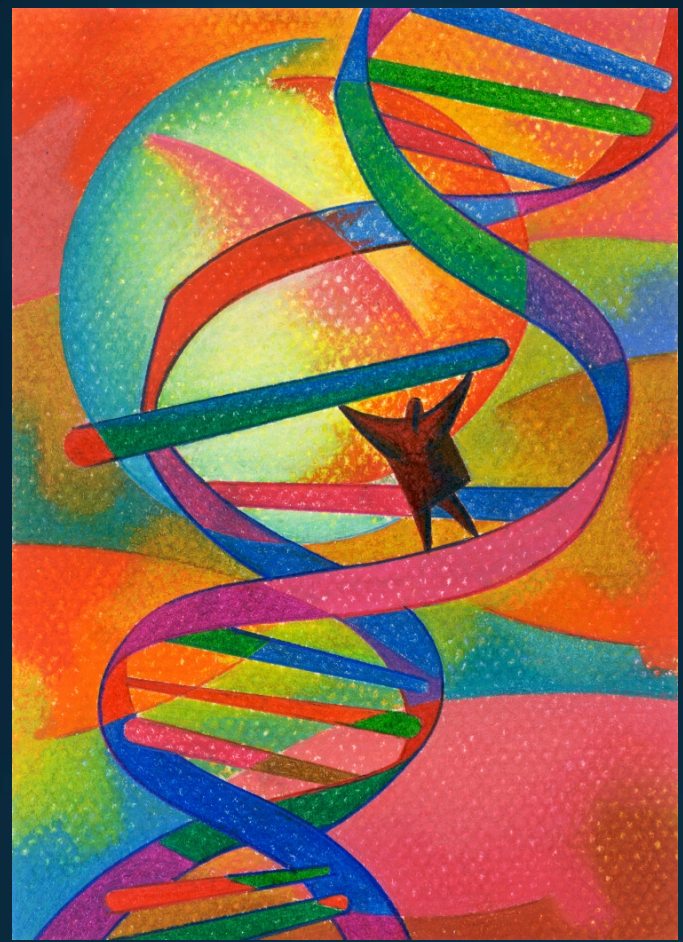
- Articles submitted to peer-reviewed journals
- Presentations and trainings to collaborators and others
- Establish education programs for the public, health care providers
- Publish Oregon third party health care provider report card

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 <u>should</u> be getting cancer genetic counseling and testing?
How many Oregonians <u>are</u> getting appropriate cancer genetic counseling and testing?

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

Medicaid database: ~157,000 enrolled adults

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

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

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

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.