



Oregon Genetics Surveillance Data

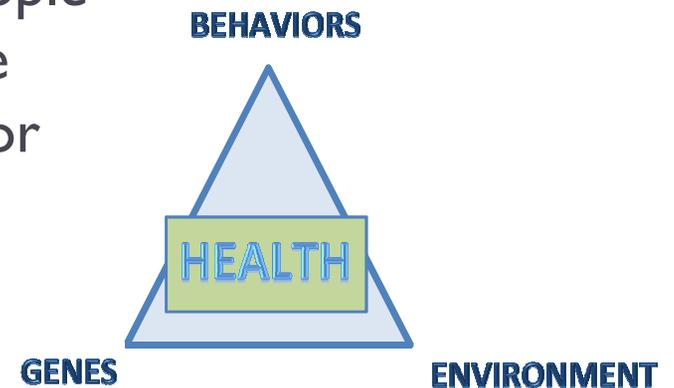
Summer Lee Cox, MPH

September 25, 2013, OPCC Data Meeting



What is cancer genomics....

- ▶ All cancers are caused by genetic mutation(s)
 - Most mutations acquired over a lifetime (somatic)
 - 5%~10% of cancer caused by an inherited mutation (germ-line)
- ▶ Cancer genomics - the molecular basis of inherited and acquired cancer
 - Public health cancer genomics helps people understand their specific risks and make informed choices about risk reduction or modified surveillance

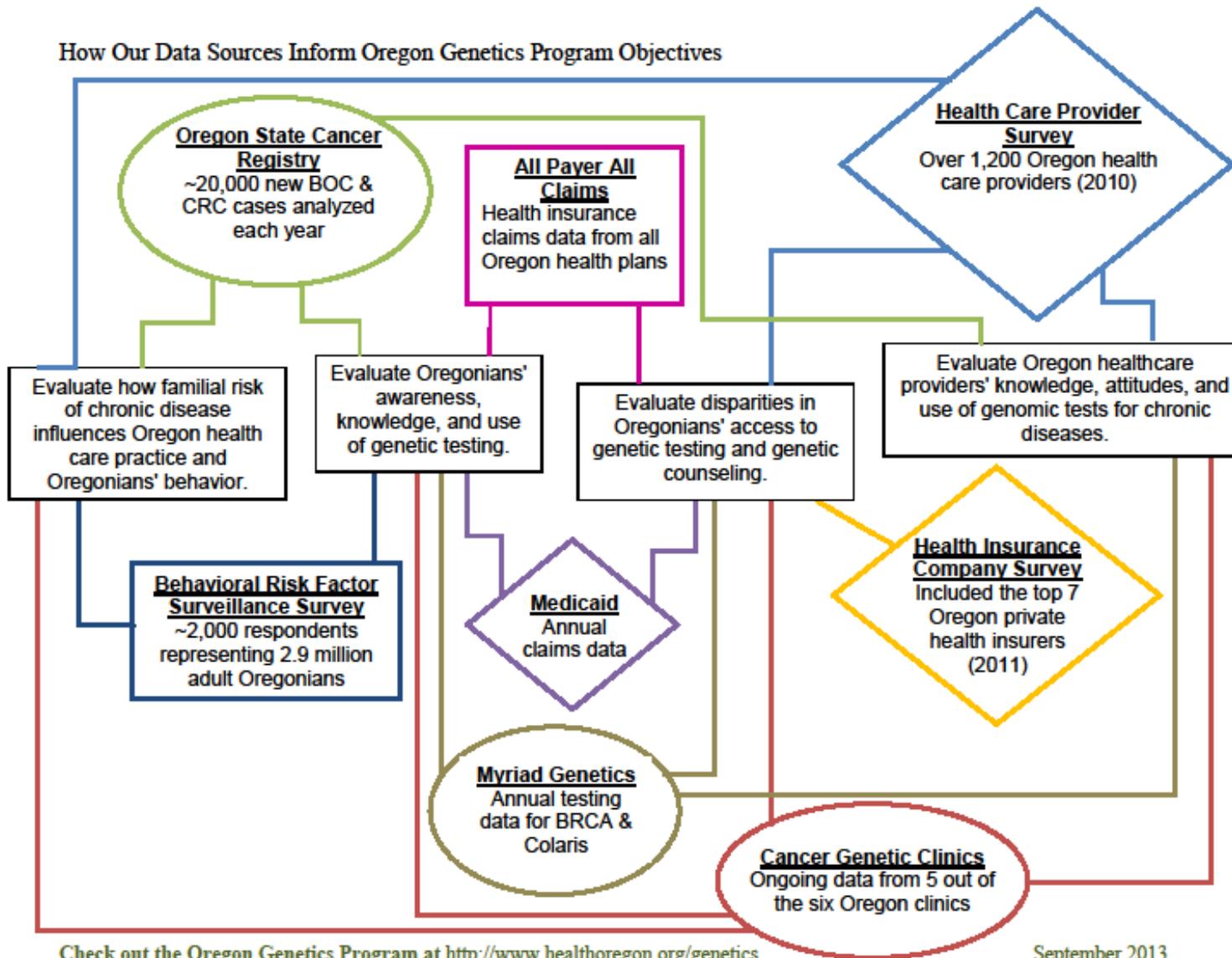


A Cancer Genetic Specialist ...

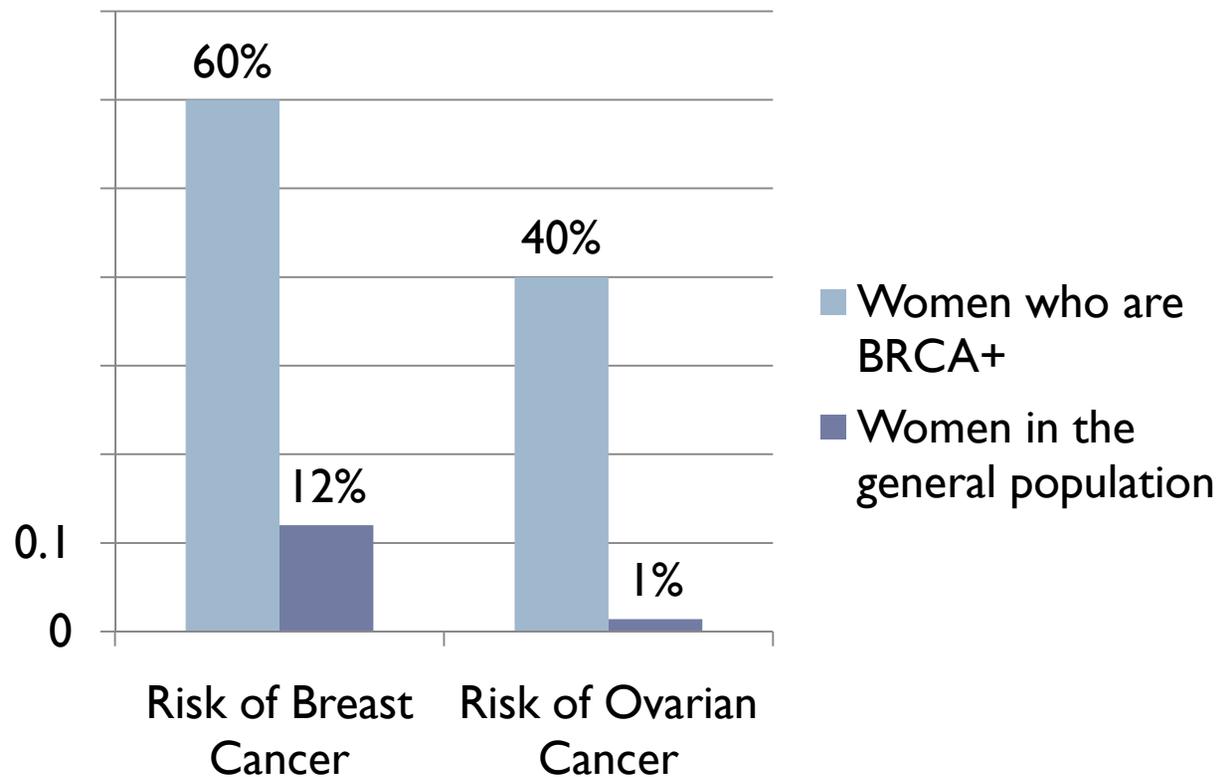
▶ Helps patients:

- Understand their likelihood of getting heritable cancers
- Make an informed decision about whether having a genetic test is the right choice
- Identify opportunities for managing risks
- Develop a personal cancer screening plan
- Provide information for family members

How Our Data Sources Inform Oregon Genetics Program Objectives

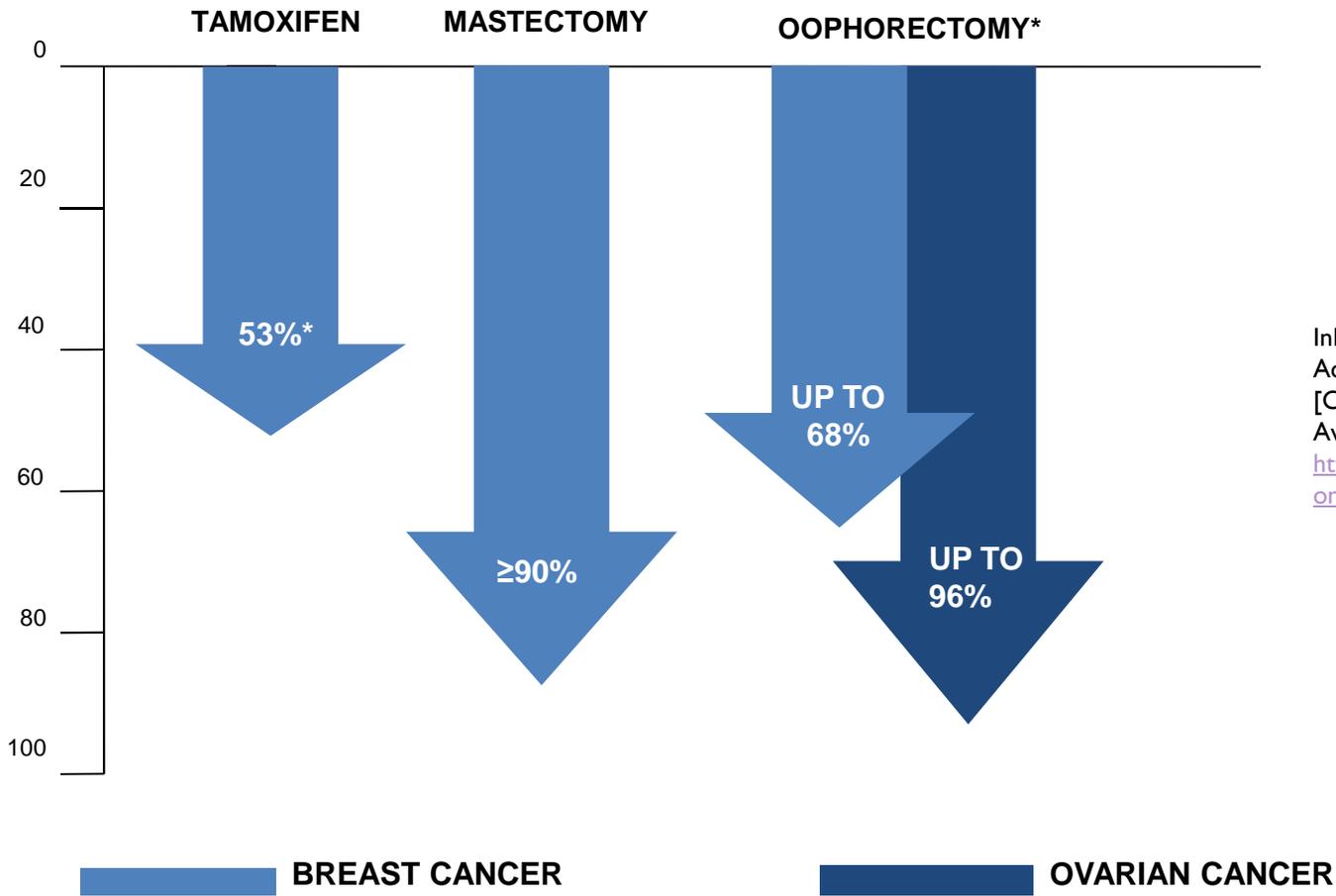


Cancer Risks: Comparing *BRCA*+ to the General Population (among Women)



National Cancer Institute (NCI). *BRCA1 and BRCA2: Cancer Risk and Genetic Testing*. 05/29/2009

Preventive measures that lower the risk of developing cancer (in women with a BRCA mutation)

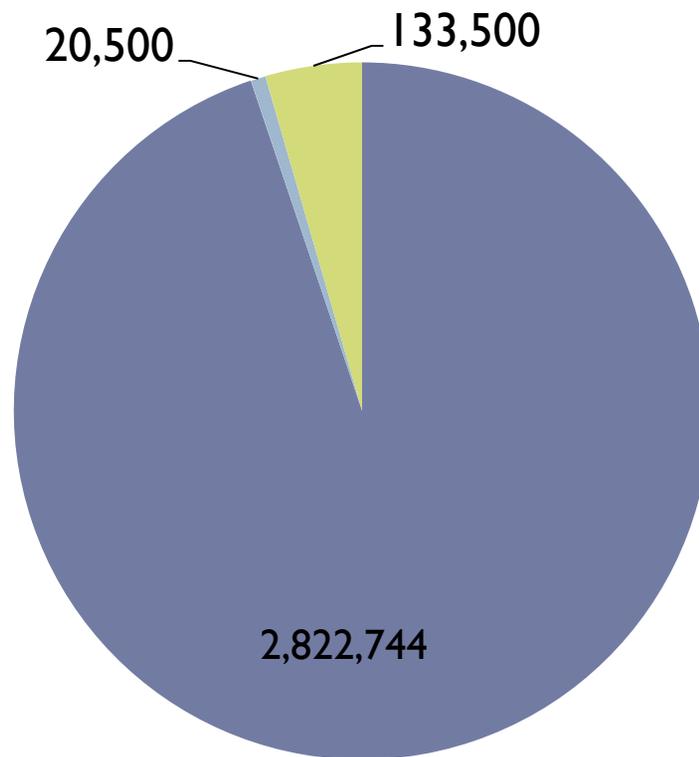


InheritedRisk.Com. Taking Action to Prevent Cancer. [Cited 2012 May 22]; Available from: <http://www.inheritedrisk.com/taking-action/>

*Oophorectomy = removal of the ovaries

Hereditary Cancer Burden in Oregon Adults

Approximately 154,000 candidates for BRCA testing



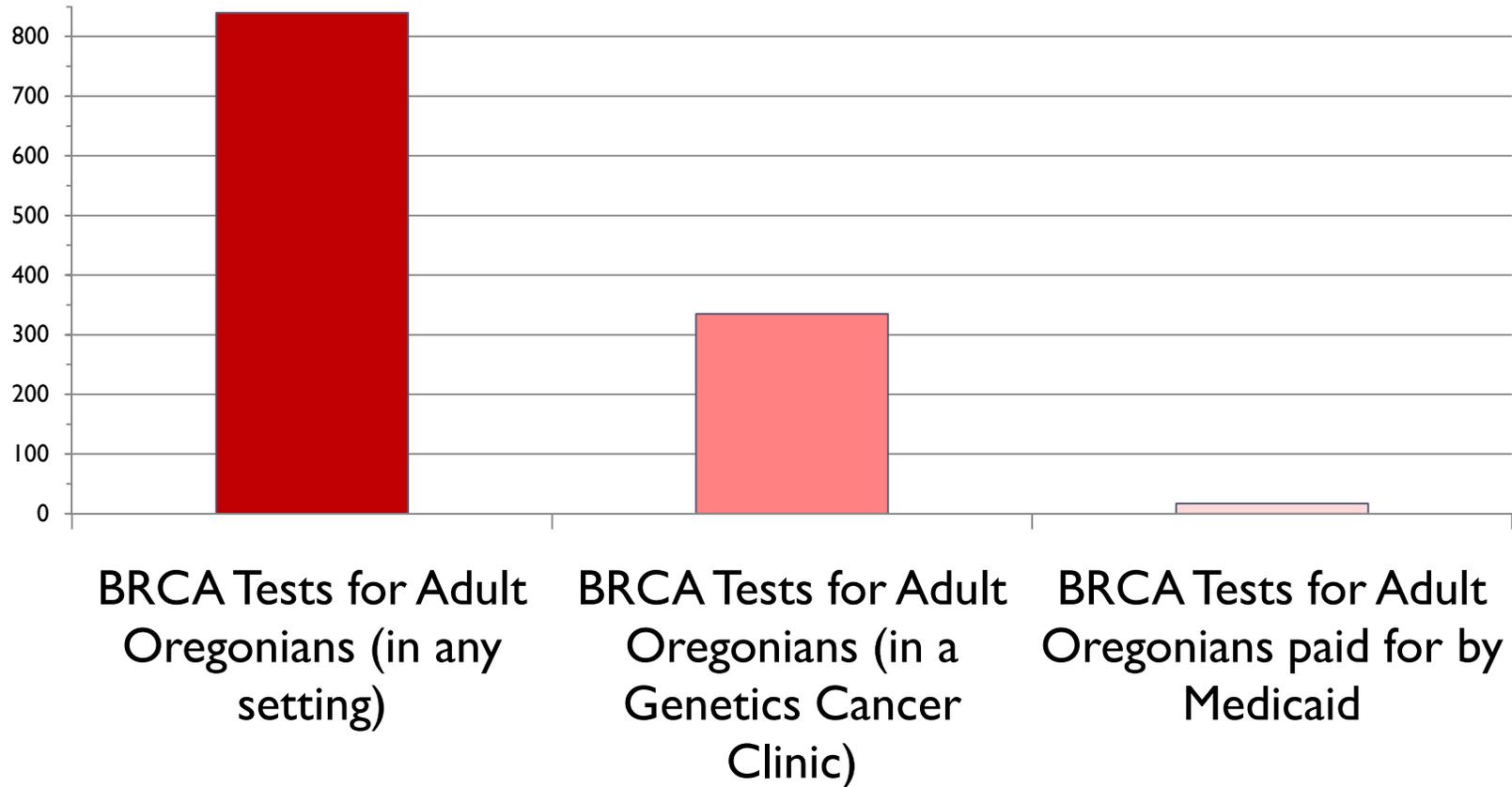
- Adult Oregonians with no family history of HBOC
- BRCA Carriers
- BRCA Testing Candidates minus BRCA Carriers

Estimated # diagnosed with cancer **per year** who are likely to have a mutation:

- ▶ BRCA: 800-1150 women
- ▶ MMR: 400-550 people

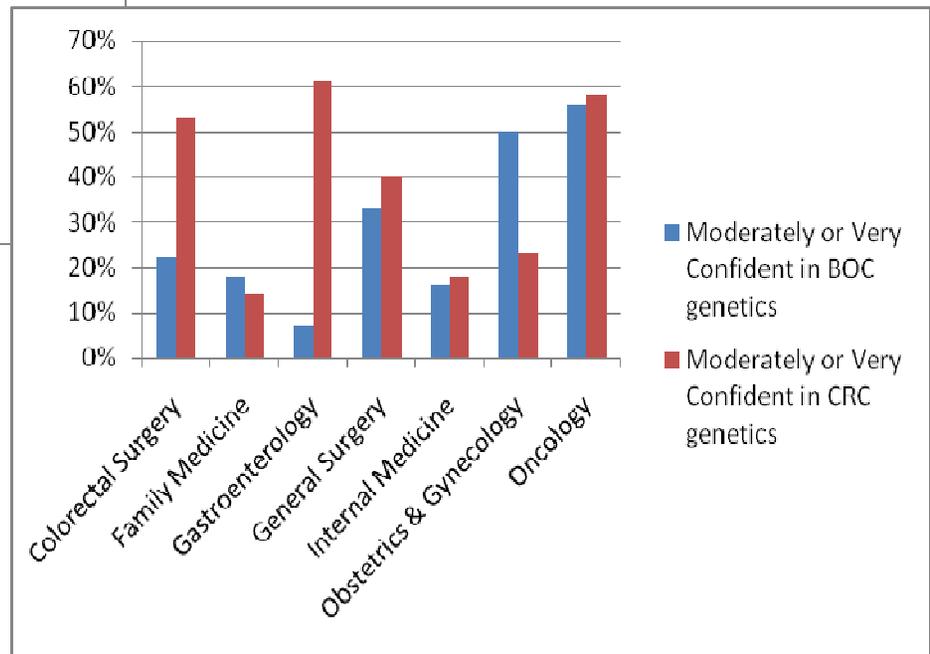
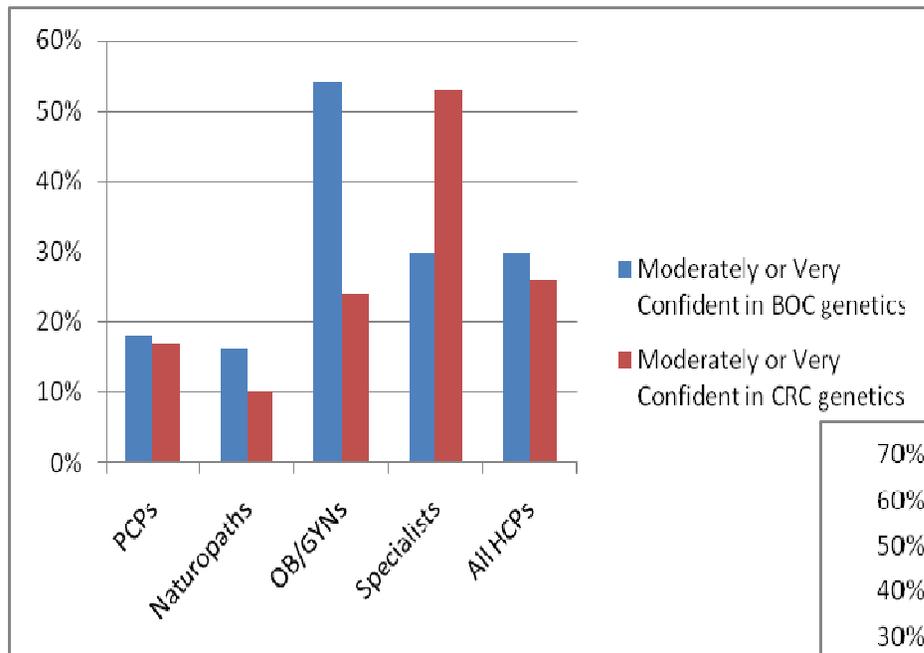
data source: Oregon Genetics Program Report: BRCA I&2 and MMR Gene Mutations in the Oregon Population: Estimating Mutation Carriers and Referrals for Genetic Services. March, 2011. Not Published.

Oregon *BRCA* Testing in 2008



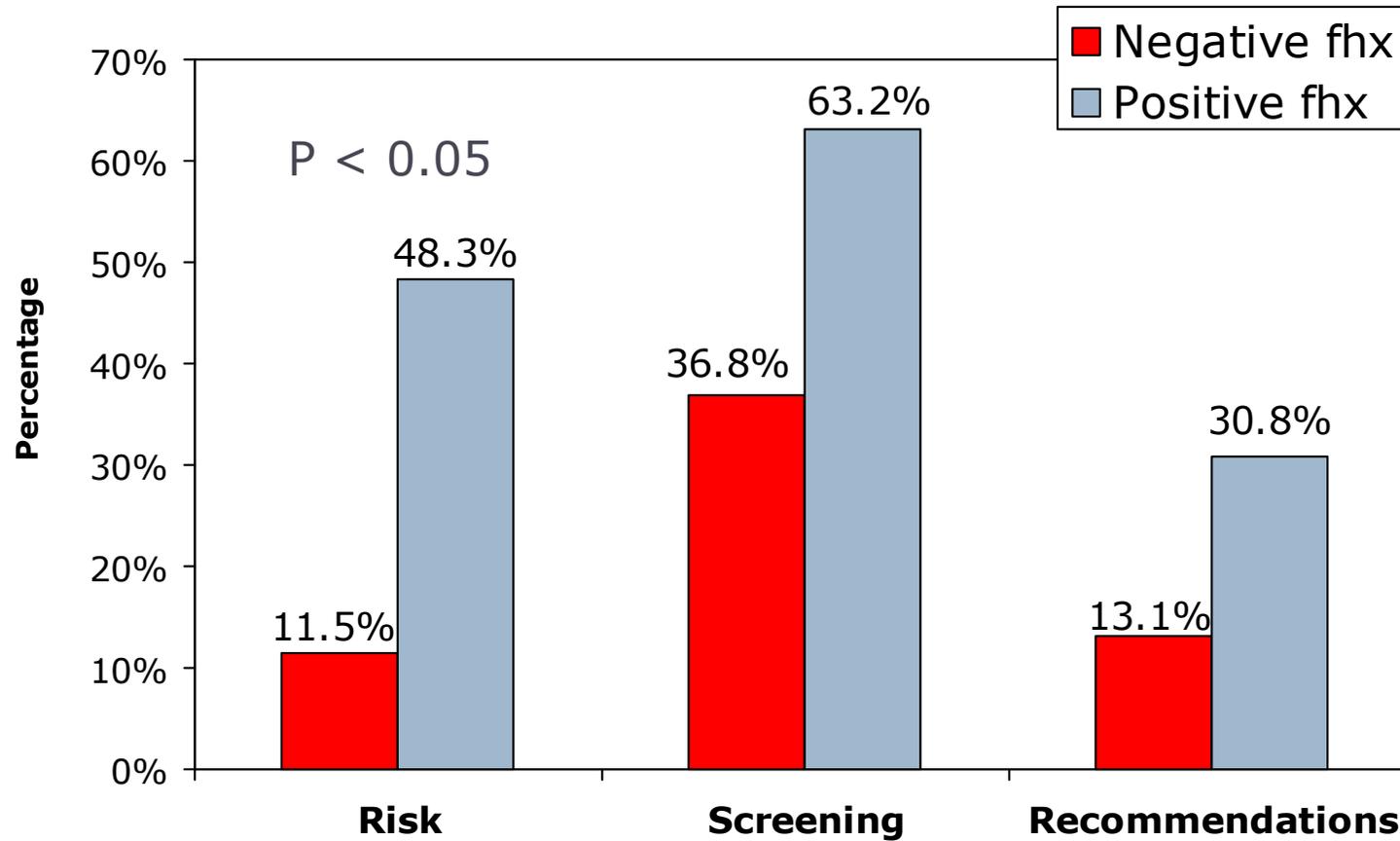
data sources: 2008 data supplied by Myriad, private communication; 2008 Oregon Genetic Services Data, unpublished; 2008-2012 OPHG Close-out Report, unpublished.

Healthcare Provider Genetics Confidence



data source: 2010 Oregon Genetics Program Healthcare Provider Survey.

Healthcare Provider Behavior: Discussion and Recommendations



data source: 2008 Behavioral Risk Factor Surveillance System, CRC awareness questions

Take home messages

- ▶ Only a small proportion of Oregonians who may benefit from genetic services are being seen in cancer genetics clinics
- ▶ Oregonians are experiencing geographic disparity in access to cancer genetic services due to the locations of the six cancer genetics clinics
- ▶ Oregonians are experiencing economic disparity in access to *BRCA* testing and likely other appropriate genetic tests
- ▶ BOC is much more recognized by healthcare providers for its hereditary components than is CRC, confidence and knowledge of cancer genetics needs to improve
- ▶ Patient and Provider Awareness of family history can mitigate risk
 - Patient-mediated effects motivate individuals to:
 - adopt behaviors that may help prevent disease
 - seek screening that may help diagnose early
 - Clinician-mediated effects motivate clinicians to:
 - counsel patients with a positive CRC family history about their risk, appropriate screenings and recommendations for behavior change

Please call or email if you have any
questions or would like resources

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Heritable Cancer Facts

- ▶ 5% ~ 10% of cancer is caused by an inherited mutation
 - Lifetime risk of developing certain types of cancer is SIGNIFICANTLY increased
 - Average age of onset is YEARS earlier
- ▶ Individuals with cancer-causing mutations
 - May need to begin screening at earlier than those at average or moderate risk
 - May need enhanced screening
 - May want to consider prophylactic measures