Cancer Genetic Testing in Oregon: Preliminary Findings from Genetics Services Provider Clinical Data

Authors: Amy I. Zlot, MPH¹, Kerry Silvey, MA, CGC^{1,1}, Nanette Newell, Ph.D¹, Nicoleta Voian, M.D. , MPH^{1,10}, Kelly Hamman, MS, CGC², Jone Sampson, M.D.², Paul Dorsey, MS, CGC³, Mary Pat Bland, MS, CGC⁴, Jacob Reiss, M.D.⁴, Katrina Goddard, Ph.D⁵, Nancy Ledbetter, RN, CNS, APNG⁶, Kristine King, M.D.², Karen Kovak, MS, CGC³, Kathryn Murray, MS CGC³, Robert Nystrom, MA¹, Katherine Bradley, Ph.D, RN¹

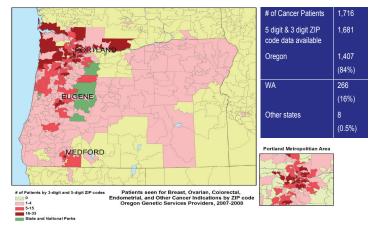
1. Oregon Genetics Program, Public Health Division, 2. Knight Cancer Institute, Oregon Health and Science University, 3. Legacy Cancer Services, 4. NW Kaiser Permanente, 5. Kaiser Center for Health Research, 6. Providence Cancer Center, 7. Providence Medical Group South, 8. Oregon Health and Science University, CDRC Genetics Clinic,
9. Center for Genetics and Maternal-Fetal Medicine, 10. Oregon Health and Science University - Denartment of Molecular and Medical Genetics, 11. Oregon Health & Science University - Child Development and Rehabilitation Center. Center for Children and Youth with Special Health Needs

Background:

In 2007 and 2008, seven Oregon genetics clinics saw patients for cancer related reasons. Of these seven clinics, five were located in the Portland metropolitan area, one in Eugene, and one in Medford. In 2008, approximately 85% of the 3.79 million Oregonians (and 2.7 million Oregonians > age 18 years) lived within 80 miles of those three metropolitan areas.

Methods:

De-identified genetic services data included: ICD-9 codes, age, ZIP code, and BRCA and MMR genetic testing for patients seen for breast, ovarian, colorectal, and endometrial cancer related reasons. Five clinics released patient-level data based on 5-digit ZIP codes, one clinic released 3-digit ZIP code data, and one clinic released 5-digit ZIP code data for ZIP codes with populations \geq 20,000 people; for ZIP codes with populations \leq 20,000 people, that clinic released 3-digit ZIP code data.





Outside of Portland, Eugene & Medford		Number and % of the Oregon adult population* seen by Genetic Services	
Population 2008	568,500	Providers for cancer reasons (per year	
Percent of Population	15%	Oregon Patients seen for Breast and	663 (0.025%)
# of Oregon Cancer Genetics Patients	16 (expected = ~ 240)	Ovarian Cancer	(0.025%)
2007-2008		Oregon Patients seen for Colorectal and	89 (0.0003%)
% of Oregon Cancer Genetics Patients	1% (expected = ~ 15%)	Endometrial Cancer *% Based on 2.7 million Oregon adu	

Results:

During 2007 and 2008, 1,716 patients were seen in Oregon genetics clinics for cancer-related reasons. Eight-four percent (1,407 patients) whose ZIP codes could be matched to a 3 or 5-digit ZIP code resided in Oregon. Eighty-three percent of all patients (1,421) were seen for breast or ovarian cancer, 13% (228 patients) were seen for colorectal cancer or endometrial cancer, and 4% (69 patients) were seen for other cancers, such as prostate cancer. One percent of patients traveled more than 80 miles for cancer genetic services; however, based on the geographic distribution of the population within the state, we would expect 15 times as many. Six of the seven clinics were able to abstract genetic testing information (for 892 patients). In these six clinics, sixty percent of breast and ovarian cancer patients had BRCA testing, and 47% of colorectal and endometrial cancer patients had MMR testing.

Discussion

Compared to the estimated carriers in the population, only a small proportion of Oregonians who may benefit from cancer genetic services are being seen in Oregon cancer genetics clinics. Access to genetic services is challenging for populations living in central and eastern Oregon, and these populations appear to be under-served by genetic services providers. These results will inform policy aimed at increasing the availability of appropriate genetic testing and counseling in Oregon. On a national level more work is needed to promote electronic medical records as a useable source of genetic testing information.



Number of Patients by 3-digit & 5 digit ZIP codes
Oregon Patients Traveling 80+ Miles for Cancer
Genetics Services 2007-2008 by ZIP code