Public Health Cancer Genomics: a state perspective

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Heartland 12th Annual Conference
<table>
<thead>
<tr>
<th>State</th>
<th>Population in millions</th>
<th>State Size (sq mi, thousands)</th>
<th>Hispanic</th>
<th>White, not Hispanic or Latino</th>
<th>Black/ African American</th>
<th>AIAN</th>
<th>Asian</th>
<th>NHPI</th>
<th>Multiple races</th>
<th>Median Household Income (thousands)</th>
<th>Per capita income (thousands)</th>
<th>Persons in Poverty</th>
<th>HS graduate or higher</th>
<th>Bachelor’s degree or higher</th>
<th>% w/o health insurance, under 65 yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arkansas</td>
<td>3.0</td>
<td>53.18</td>
<td>7.2%</td>
<td>79.5%</td>
<td>15.7%</td>
<td>1.0%</td>
<td>1.6%</td>
<td>0.3%</td>
<td>2.0%</td>
<td>$41</td>
<td>$23</td>
<td>19.1%</td>
<td>84.3%</td>
<td>20.6%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Iowa</td>
<td>3.1</td>
<td>56.27</td>
<td>5.7%</td>
<td>86.7%</td>
<td>3.5%</td>
<td>0.5%</td>
<td>2.4%</td>
<td>0.1%</td>
<td>1.8%</td>
<td>$53</td>
<td>$28</td>
<td>12.2%</td>
<td>91.3%</td>
<td>26.4%</td>
<td>5.9%</td>
</tr>
<tr>
<td>Kansas</td>
<td>2.9</td>
<td>82.28</td>
<td>11.6%</td>
<td>76.4%</td>
<td>6.3%</td>
<td>1.2%</td>
<td>2.9%</td>
<td>0.1%</td>
<td>2.9%</td>
<td>$52</td>
<td>$27</td>
<td>13.0%</td>
<td>90.0%</td>
<td>30.7%</td>
<td>10.6%</td>
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<tr>
<td>Missouri</td>
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<td>69.71</td>
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<td>79.8%</td>
<td>11.8%</td>
<td>0.6%</td>
<td>2.0%</td>
<td>0.1%</td>
<td>2.2%</td>
<td>$48</td>
<td>$26</td>
<td>14.8%</td>
<td>88.0%</td>
<td>26.7%</td>
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<tr>
<td>Nebraska</td>
<td>1.9</td>
<td>77.35</td>
<td>10.4%</td>
<td>80.0%</td>
<td>5.0%</td>
<td>1.4%</td>
<td>2.3%</td>
<td>0.1%</td>
<td>2.1%</td>
<td>$52</td>
<td>$27</td>
<td>12.6%</td>
<td>90.5%</td>
<td>29.0%</td>
<td>9.5%</td>
</tr>
<tr>
<td>North Dakota</td>
<td>0.8</td>
<td>70.70</td>
<td>3.5%</td>
<td>85.8%</td>
<td>2.4%</td>
<td>5.5%</td>
<td>1.4%</td>
<td>0.2%</td>
<td>2.1%</td>
<td>$56</td>
<td>$31</td>
<td>11.0%</td>
<td>91.3%</td>
<td>27.3%</td>
<td>8.9%</td>
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<tr>
<td>Oklahoma</td>
<td>3.9</td>
<td>69.90</td>
<td>10.1%</td>
<td>66.5%</td>
<td>7.8%</td>
<td>9.1%</td>
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<td>0.1%</td>
<td>6.0%</td>
<td>$46</td>
<td>$25</td>
<td>16.1%</td>
<td>86.7%</td>
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<td>16.2%</td>
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<tr>
<td>South Dakota</td>
<td>0.9</td>
<td>77.12</td>
<td>3.6%</td>
<td>82.9%</td>
<td>1.8%</td>
<td>8.9%</td>
<td>1.4%</td>
<td>0.1%</td>
<td>2.2%</td>
<td>$50</td>
<td>$26</td>
<td>13.7%</td>
<td>90.7%</td>
<td>26.7%</td>
<td>12.0%</td>
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<tr>
<td>Oregon</td>
<td>4.0</td>
<td>98.38</td>
<td>12.7%</td>
<td>76.6%</td>
<td>2.1%</td>
<td>1.8%</td>
<td>4.4%</td>
<td>0.4%</td>
<td>3.7%</td>
<td>$51</td>
<td>$27</td>
<td>15.4%</td>
<td>89.5%</td>
<td>30.1%</td>
<td>8.3%</td>
</tr>
</tbody>
</table>
American Public Health Association (APHA)

• APHA Policy Statements
  • Advancing Cancer Genomics in Public Health
    o Date: November 5, 2013
    o Policy Statement Number: 201317
  • Strengthening Genetic and Genomic Literacy
    o Date: November 10, 2010
    o Policy Statement Number: 201012
  • The Role of Genomics in Public Health
    o Date: November 13, 2002
    o Policy Statement Number: 20021
  • Guidelines for Genetic Testing in Industry
    o Date: January 1, 1983
    o Policy Statement Number: 8310
The *BRCA* Mutation Increases Your Risk of Cancer... *(this slide shows a woman’s risk only)*

...But Proactive Cancer Management Can Reduce the Risk

CDC Support of Public Health Genomics

• CDC Cooperative Agreement, 2003-2008
  • Office of Public Health Genomics
  • Awarded to Michigan, Minnesota, Oregon, and Utah
  • Integrated genomics knowledge (e.g., genetic risk factors) and tools (e.g., family history assessments) into state chronic disease prevention programs and core public health functions.

• CDC Cooperative Agreement, 2008-2011
  • Office of Public Health Genomics
  • Awarded to Michigan, and Oregon
  • Focused on opportunities to use public health strengths of surveillance, education, and policy development to promote and monitor implementation of newly emerging evidence-based genomic testing and family health history recommendations.
CDC Support of Public Health Genomics

• CDC Cooperative Agreement, 2011-2014
  o Division of Cancer Prevention and Control
  o Georgia, Michigan, and Oregon
  o Enhance the capacities of state health departments to promote the application of best practices for evidence-based breast cancer genomics through education, surveillance, and policy activities related to hereditary breast and ovarian cancer (HBOC).

• CDC Cooperative Agreement, 2014-2019
  o Division of Cancer Prevention and Control
  o Colorado, Connecticut, Michigan, Oregon, and Utah
  o Promote the adoption of cancer genomics best practices for Hereditary Breast and Ovarian Cancer (HBOC) and Lynch Syndrome (LS). The long-term goal is to reduce the incidence and mortality of hereditary cancers, especially breast cancer at a young age, ovarian cancer, endometrial cancer, and colorectal cancer.
Healthy People 2020 (HP2020) Objectives

- Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling (G1)
- Increase the proportion of persons with newly diagnosed colorectal cancer who received genetic testing to identify Lynch syndrome (G2)
- Reduce the overall cancer death rate (C1)
- Reduce the female breast cancer death rate (C3)
- Reduce late-stage female breast cancer (C11)
Hereditary Cancer & Evidence-based Guidelines

• National Comprehensive Cancer Network (NCCN) Guidelines for Detection, Prevention, & Risk Reduction
  o Genetic/Familial High-Risk Assessment: Breast and Ovarian
  o Genetic/Familial High-Risk Assessment: Colorectal

• USPSTF BRCA-Related Cancer: Risk Assessment, Genetic Counseling, and Genetic Testing – December 2013
  o Grade B and Grade D Recommendations

• EGAPP Working Group Recommendation: genetic testing strategies in newly diagnosed individuals with colorectal cancer aimed at reducing morbidity and mortality from Lynch syndrome in relatives - January 2009
Tier 1 Genetic/Genomic Applications

• 3,000+ genetic tests available to clinicians
  ○ 59 Genomic Applications (tests, tools, screenings) w/ clinical utility & validity, and analytic validity
    • CDC Office of Public Health Genomics – Genomic Testing, Genomic Tests by Level of Evidence
State Health Departments Utilize Core Public Health Functions

Assessment:
- Regular systematic collection, assembly, analysis, and dissemination of information, including genetic epidemiologic information

Policy Development:
- Formulation of standards and guidelines, in collaboration with stakeholders, which promote the appropriate use, effectiveness, accessibility, and quality of genetic services and tests

Assurance:
- Appropriate use of genomic information and genetic tests and services meet agreed upon goals for effectiveness, accessibility, and quality

Slide provided by Debra Duquette, MS, CGC, of Michigan Department of Health and Human Services
ScreenWise Genetics Current Work

• Promote and apply evidence-based hereditary cancer genomics best practices
  o HBOC & LS
  o Public health, health care, and health insurance settings
  o Using education, policy/systems change, partnerships, and surveillance approaches
    1) Increase appropriate use of genetic and associated clinical services by public and health care providers;
    2) Improve access to genetic and associated clinical services for high-risk individuals; and
    3) Improve coverage of genetic and associated clinical services for high-risk individuals.
ScreenWise Integration of Genomics

• ScreenWise Program = Oregon Breast & Cervical Cancer Program + WISEWOMAN + Oregon Genetics Program
  o Forms
  o Provider Manual
  o Website
  o Provider trainings
• Komen grant to offer reimbursement for genetic services
Oregon State Cancer Registry (OSCaR)

- Statewide population-based cancer registry
- Established by the 1995 Oregon legislature
- To provide information to design, target, monitor, facilitate and evaluate efforts to determine the causes or sources of cancer and benign tumors among the residents of Oregon
  - Reduce burden of cancer and benign tumors
- Able to communicate with cancer survivors & reporting physicians through registry
Example of a Long-Term Outcome

Oregon female breast cancer mortality, 0-50 years, 1999-2014, crude rates per 100,000 population
Examples of SW & OSCaR Activities

• Conduct cancer genomics surveillance using registry and mortality data
  • Existing cancer incidence and mortality data analyzed through ‘genomics lens’
  • Analyze tumor characteristics stratified by other variables to identify trends
  • Identify cases at high risk by age, gender, cancer type, race/ethnicity, ZIP code, etc
• OSCaR Letter Intervention & Survey
  – Breast cancer at ≤ 50 years
  – Triple negative (ER-, PR-, HER2-) breast cancer
  – Ovarian cancer
  – Males with breast cancer
Genetic Counseling and Testing Among Respondents (n = 399)

- 41% Had genetic counseling & genetic testing (n=163)
- 8% Had genetic counseling only (n=24)
- 13% Had genetic testing only (n=52)
- 6% Had neither counseling nor testing (n=127)
- 45% Other (n=33)

[Pie chart showing the distribution of respondents according to their genetic counseling and testing experiences]
Reasons for NOT receiving genetic counseling or testing services

Asked only of those who did not respond "Yes" to having received a BRCA genetic test

- Never recommended (n=92)
- Did not know they existed (n=24)
- A doctor told me not to go (n=12)
- Medical insurance coverage issues (n=39)
- Concern about genetic discrimination (n=13)
- Too nervous, don't want to know risk (n=12)
- Not enough time, too busy (n=6)
- Lack of transportation or distance (n=4)
- Poor health makes appts difficult (n=2)
- Lack of child care or other support (n=1)
- Other (n=31)

56%
14%
7%
23%
8%
7%
4%
2%
1%
18%
Self-reported genetic counseling status and awareness of BRCA genetic test among females with USPSTF increased-risk family histories, 2011 Oregon BRFSS

- 63% No genetic counseling, had NOT heard of BRCA test
- 27% No genetic counseling, heard of BRCA test
- 10% Rec'd genetic counseling
Was this Project Successful?

Oregon cancer survivors who responded positively to the letters

<table>
<thead>
<tr>
<th></th>
<th>Learned new information</th>
<th>Believe information was useful</th>
<th>Prompted or will prompt action</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percent(^1)  Odds Ratio</td>
<td>Percent(^1)  Odds Ratio</td>
<td>Percent(^1)  Odds Ratio</td>
</tr>
<tr>
<td>Total</td>
<td>42.3</td>
<td>54.5</td>
<td>26.9</td>
</tr>
<tr>
<td>Received Counseling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>24.9 1.000(^2)</td>
<td>45.1 1.000(^2)</td>
<td>13.1 1.000(^2)</td>
</tr>
<tr>
<td>No</td>
<td>57.1 4.017***</td>
<td>63.4 2.103***</td>
<td>40.0 4.417***</td>
</tr>
<tr>
<td>Received Testing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27.2 1.000(^2)</td>
<td>46.1 1.000(^2)</td>
<td>12.0 1.000(^2)</td>
</tr>
<tr>
<td>No</td>
<td>61.6 4.294***</td>
<td>64.9 2.163***</td>
<td>47.0 6.475***</td>
</tr>
</tbody>
</table>

\(^1\) Percent in each category that responded "Strongly Agree" or "Agree" to the question. Denominator excludes missing responses.

\(^2\) Logistic regression reference category.

\(***p\leq.001\)
Other examples of work & findings

• Data from Cancer Genetic Clinics
  • Hispanic/Latino and Blacks were less likely than White/Other to use cancer genetic services

• Promoting Cancer Genomics Best Practices to Health Plans
  • Medicaid & private health plans

• Other data sources
  • All Payers All Claims and Medicaid
  • BRFSS
State Comprehensive Cancer Control Plans & Genomic Content


<table>
<thead>
<tr>
<th>State</th>
<th>Period Covered by CCC Plan</th>
<th>Genomics-Related Goal, Objective, or Strategy</th>
<th>Core Public Health Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Began</td>
<td>Ends</td>
<td>Assessment</td>
</tr>
<tr>
<td>Arkansas</td>
<td>NS</td>
<td>NS</td>
<td>Yes</td>
</tr>
<tr>
<td>Iowa</td>
<td>2006</td>
<td>2011</td>
<td>Yes</td>
</tr>
<tr>
<td>Kansas</td>
<td>2005</td>
<td>NS</td>
<td>No</td>
</tr>
<tr>
<td>Missouri</td>
<td>2004</td>
<td>NS</td>
<td>No</td>
</tr>
<tr>
<td>Nebraska</td>
<td>2004</td>
<td>2010</td>
<td>Yes</td>
</tr>
<tr>
<td>North Dakota</td>
<td>2006</td>
<td>2010</td>
<td>Yes</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>2007</td>
<td>NS</td>
<td>No</td>
</tr>
<tr>
<td>South Dakota</td>
<td>2005</td>
<td>2010</td>
<td>Yes</td>
</tr>
<tr>
<td>Oregon</td>
<td>2005</td>
<td>2010</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Lynch Syndrome Screening Network (LSSN)

- **LSSN Vision:**
  - To reduce the cancer burden associated with Lynch syndrome.

- **LSSN Mission:**
  - To promote universal Lynch syndrome screening on all newly diagnosed colorectal and endometrial cancers;
  - to facilitate the ability of institutions to implement appropriate screening by sharing resources, protocols and data through network collaboration; and
  - to investigate universal screening for other Lynch syndrome related malignancies

- http://www.lynchscreening.net/

- Created in 2011 with one-time funding from CDC; small amount of funding from NCI

- Membership is by institution
  - Over 120 leading cancer institutions are members
    - Kintalk.org created by UCSF to promote cascade testing
  - No cost to join
  - Website with multiple resources to assist institutions to implement Lynch syndrome screening
  - Active listserv
  - Database in development
  - Research and networking opportunities
  - Membership data assisting to measure HP2020 Lynch syndrome objective
    - Over 20,000 cancers screened since 2008

Slide provided by Debra Duquette, MS, CGC, of Michigan Department of Health and Human Se
Thank You!

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