Outreach to Individuals at Risk for Lynch Syndrome from a Cancer Registry

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University of Colorado Cancer Center; Colorado School of Public Health; Colorado Central Cancer Registry

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Project Purpose

• Increase awareness about hereditary colon cancer among providers and their at-risk patients using a central cancer registry

• Assess feasibility and acceptability of direct-to-patient outreach from a cancer registry
Methods

• Applied **Bethesda criteria** to registry data:
  – CRC under age 50; metachronous/synchronous CRC or other Lynch syndrome related cancers; CRC <60 with MSI histology

• Contacted **providers** to obtain consent
  – 80% who responded said OK contact patients
  – Opportunity for **provider education**

• Mailed educational brochure to patients (n=226)
  – Provided resource directory of genetic counselors in Colorado and toll-free # to call with questions

• Mailed surveys at initial contact and 4 months
Patient Initial Survey: How Did You Feel About Getting the Information? (n=43 responses)

- Glad: 77%
- Know more: 42%
- Angry: 0%
- Concerned or worried: 10%
- No strong feelings: 12%
Patient Initial Survey: Should the Registry Send Out Information to Individuals At-Risk?

- Yes, MD Consent: 71%
- Yes, No MD Consent: 22%
- No: 7%
Patient Follow-up Survey: Have You Discussed Cancer Risk Assessment With Anyone? (n=67)

- MD: 24%
- Genetic Counselor: 3%
- Friends: 16%
- Family: 16%
- No: 60%
Patient Follow-up Survey: In the Past 4 Months, Did You Have a Cancer Risk Assessment or Intend to in the Near Future?

- Yes: 32%
- No: 48%
- Not sure: 20%
Project Summary

• Outreach was well-received by providers and patients

• Mail-based approach was effective in getting people to talk about risk assessment

• Using cancer registry for outreach about hereditary cancer is a viable approach
  – Critical to have registry support and genetic counselors involved

• Next steps
  – Larger study; longer follow-up to assess outcomes
  – Expand case group using NCCN guidelines
# Number of CRC patients at-risk for Lynch Syndrome in Colorado

<table>
<thead>
<tr>
<th>NCCN Criteria</th>
<th>Number of Cases 2012-13</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRC &lt;50</td>
<td>332</td>
</tr>
<tr>
<td>CRC 50-59 with MSI histology</td>
<td>54</td>
</tr>
<tr>
<td>Endometrial &lt;50</td>
<td>169</td>
</tr>
<tr>
<td>CRC or Endometrial &gt;50 with 2\textsuperscript{nd} Lynch related cancer</td>
<td>257</td>
</tr>
<tr>
<td>MSI high; IHC abnormal</td>
<td>11 (70% no test)</td>
</tr>
<tr>
<td>Family history</td>
<td>??</td>
</tr>
<tr>
<td>TOTAL CASES AT-RISK</td>
<td>823 or &gt;400 per year</td>
</tr>
</tbody>
</table>

**Missing cases due to lack of family history and MSI/IHC status**

Completed by: Alex Schneider, MPH candidate
Adoption of Universal Testing and Family History Collection

- Surveyed 47 tumor registrars from 29 hospitals

<table>
<thead>
<tr>
<th>Question</th>
<th>% Yes</th>
</tr>
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<tbody>
<tr>
<td>Universal Testing</td>
<td></td>
</tr>
<tr>
<td>Hospital implementing now?</td>
<td>57%</td>
</tr>
<tr>
<td>Planning on in future?</td>
<td>2%</td>
</tr>
<tr>
<td>What test are you using?</td>
<td>MSI (70%) IHC (62%)</td>
</tr>
<tr>
<td>Using information to refer patients for risk assessment?</td>
<td>45%</td>
</tr>
<tr>
<td>Family Cancer History</td>
<td></td>
</tr>
<tr>
<td>Family History in medical record?</td>
<td>97%</td>
</tr>
<tr>
<td>How collected?</td>
<td>Text / Discrete / Both</td>
</tr>
<tr>
<td></td>
<td>67% / 9% / 21%</td>
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Acknowledgment: Dr. Joe Denagy, Preventive Medicine Resident