Educational Outreach to Individuals at Risk for Hereditary Colon Cancer

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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 or synchronous CRC or other Lynch syndrome related cancers
  – CRC under age 60 with MSI histology

• Contacted providers to obtain consent to contact patients
  – Included brochure about hereditary CRC

• Mailed brochure to patients
  – Provided resource directory of genetic counselors in Colorado and toll-free # to call with questions

• Mailed surveys at initial contact and 4 months
Project Flowchart

800 cases identified

434 physicians identified
Sent educational packets and survey

207 responded (48%)

34 no consent

169 consented (82%)

43 responses
initial survey (24%)

226 patients mailed educational packet and survey

44 bad addresses

169 follow up surveys sent

67 responses (40%)
## Physician Survey (n=169)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the information easy to understand?</td>
<td>95%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Will the information be useful to your patients?</td>
<td>85%</td>
<td>2%</td>
<td>13%</td>
</tr>
<tr>
<td>Do you provide information about cancer and genetics to your patients?</td>
<td>77%</td>
<td>21%</td>
<td>2%</td>
</tr>
<tr>
<td>The registry should send information to cases at risk, no physician consent needed</td>
<td>60%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The registry should send information, consent is needed</td>
<td>30%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The registry should not send information</td>
<td></td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Not sure if registry should send information</td>
<td></td>
<td></td>
<td>7%</td>
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</table>
Patient Initial Survey: How Did You Feel About Getting the Information? (n=43)

- 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)
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
  – Challenge is finding a way to sustain outreach by incorporating this into normal registry operations, minimizing cost and staff time

• Next steps
  – Expand case group to include MSI/IHC results
  – Apply similar strategy for hereditary breast/ovarian cancer
  – Can we use this strategy to reach family members?