Cancer Detection Using State Registries in Nationwide Cohort studies such as The Adventist Health Study 2 (AHS-2)

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The Problem

- AHS-2 members in all states
- Logistics of separate negotiations with 50 state registries (including DC)
  - State-specific IRB approval
  - Record Linkage Logistics
Black Enrollment Goals by region:
darker shade equals higher goal
### Goal by Region

**Black Adventists**

<table>
<thead>
<tr>
<th>Region</th>
<th>Rank</th>
<th>#subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Southern</td>
<td>(1)</td>
<td>14,958</td>
</tr>
<tr>
<td>Atlantic</td>
<td>(2)</td>
<td>9,373</td>
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<tr>
<td>Columbia</td>
<td>(3)</td>
<td>6,926</td>
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<tr>
<td>Pacific</td>
<td>(4)</td>
<td>4,428</td>
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<tr>
<td>Lake</td>
<td>(5)</td>
<td>3,877</td>
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<tr>
<td>S. Western</td>
<td>(6)</td>
<td>3,422</td>
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<tr>
<td>Mid-America</td>
<td>(7)</td>
<td>1,692</td>
</tr>
<tr>
<td>N. Pacific</td>
<td>(8)</td>
<td>424</td>
</tr>
</tbody>
</table>

**Total** 44,676
White Enrollment Goals by region:

darker shade equals higher goal
# Goal by Region

**White Adventists**

<table>
<thead>
<tr>
<th>Region</th>
<th>Rank</th>
<th># subjects</th>
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</thead>
<tbody>
<tr>
<td>Pacific</td>
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<td>Southern</td>
<td>(2)</td>
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<td>Columbia</td>
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<td>S. Western</td>
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<tr>
<td>Lake</td>
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<td>7,343</td>
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<tr>
<td>Atlantic</td>
<td>(8)</td>
<td>3,717</td>
</tr>
</tbody>
</table>

Total: 80,100
### Year we hope to do first link, by state

- **End 2006**
  - AK  AZ  CA  CO  IA  ID  IL  IN  KS  MI  MO  MN  MT  MA  ND  NE  NV  OR  SD  UT
  - WA  WI  WY

- **End 2007**
  - AR  CT  LA  MA  ME  NC  NH  NM  NY  OH  OK  SC  TX  VT

- **End 2008**
  - AL  DC  DE  FL  GA  KY  MD  MS  NJ  PE
  - TN  VA  WV
Could approval process be made more uniform across registries?

Proposed criteria for study to receive executive approval

- Peer review
- Federal approval
- Adequate funding
- Annual documentation that data are maintained in a secure and confidential environment
Traveling Linkage Programmers

• AHS-2 programmers work at your registry
• Use laptop
  • With AHS-2 file on it
  • To do linkage
• Delete your registry file from laptop before leaving
• Can be done with or without supervision by your registry personnel
Discussion Points

• Approval-question for each registry
  • Is executive approval feasible?
  • Usual time from submission to approval
• Linkage-options
  • Sending visiting AHS programmers to do linkage
  • Paying registries to do file linkage
  • Providing registries names of cohort members who self-report incident or prevalent cancers