

Cancer Detection Using State Registries

in Nationwide Cohort studies such as The Adventist Health Study 2
(AHS-2)

Susan Preston-Martin, Ph.D.

University of Southern California, Los Angeles, Ca.

Gary Fraser, M.D.

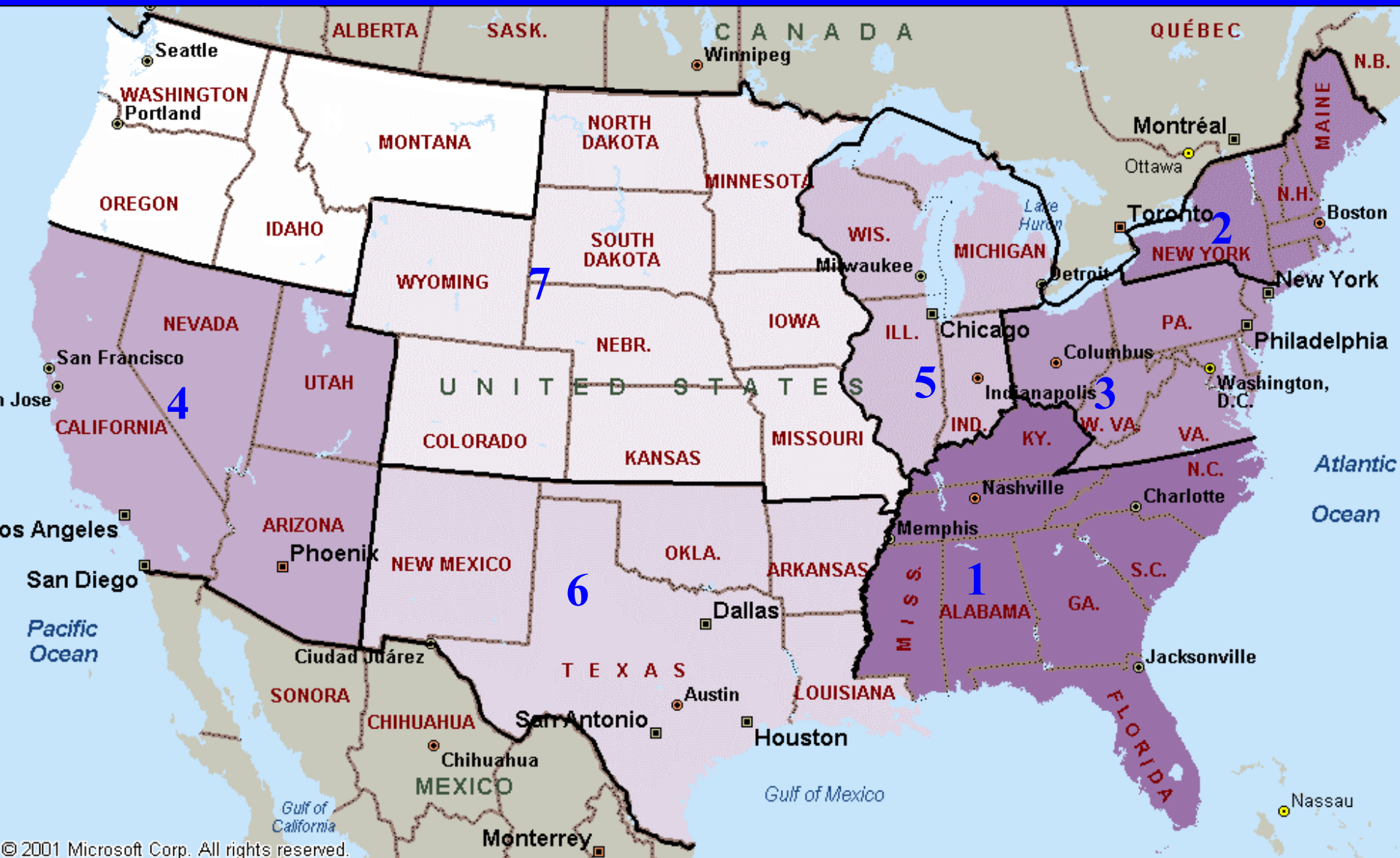
Loma Linda University, Loma Linda, Ca.

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



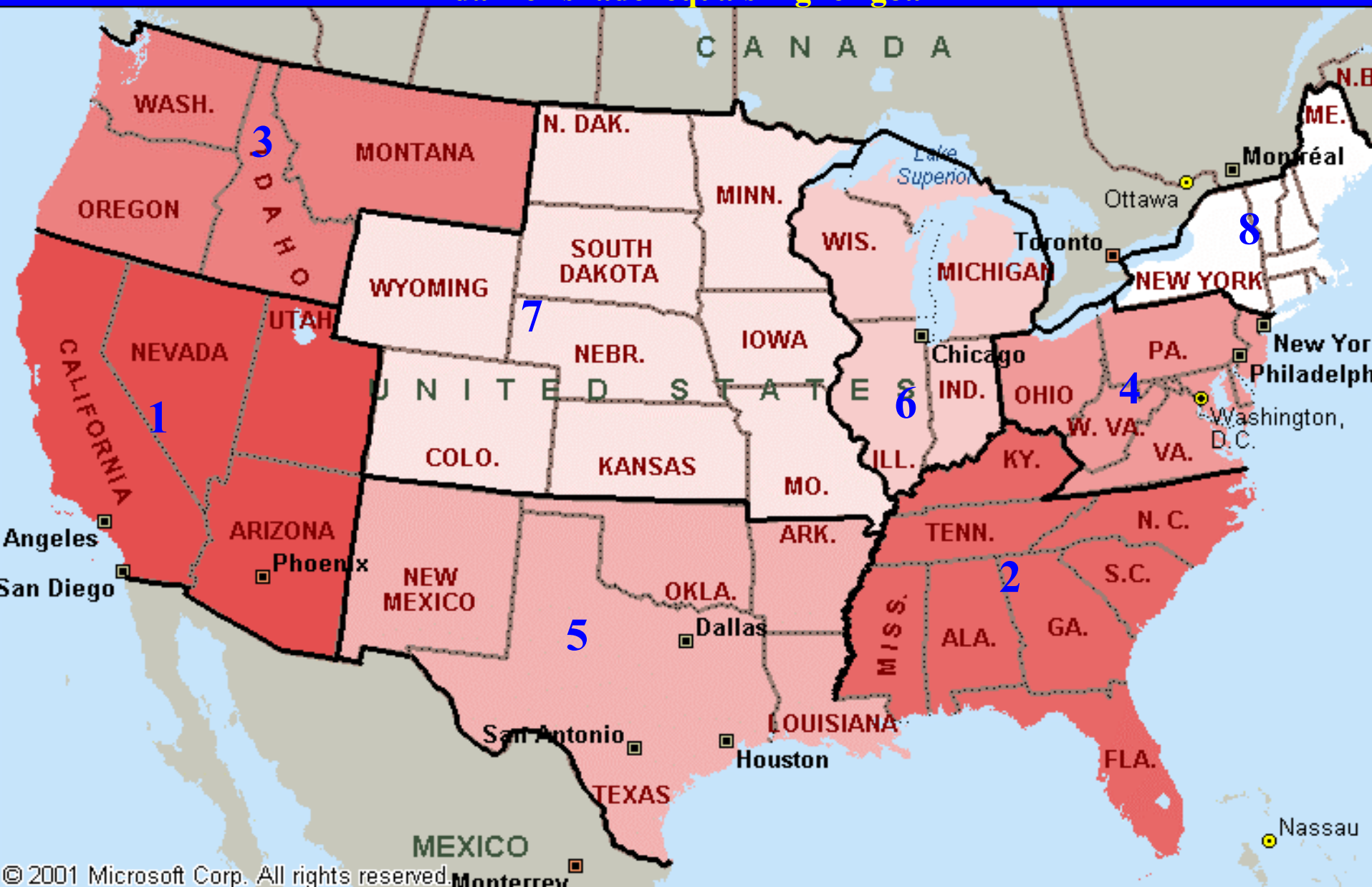
Goal by Region

Black Adventists

| <u>Region</u> | <u>Rank</u> | <u>#subjects</u> |
|---------------|-------------|------------------|
| Southern | (1) | 14,958 |
| Atlantic | (2) | 9,373 |
| Columbia | (3) | 6,926 |
| Pacific | (4) | 4,428 |
| Lake | (5) | 3,877 |
| S. Western | (6) | 3,422 |
| Mid-America | (7) | 1,692 |
| N. Pacific | (8) | 424 |
| | Total | <hr/> 44,676 |

White Enrollment Goals by region:

darker shade equals higher goal



Goal by Region

White Adventists

| <u>Region</u> | <u>Rank</u> | <u># subjects</u> |
|---------------|-------------|-------------------|
| Pacific | (1) | 19,812 |
| Southern | (2) | 14,556 |
| N. Pacific | (3) | 11,523 |
| Columbia | (4) | 8,227 |
| S. Western | (5) | 7,506 |
| Lake | (6) | 7,416 |
| Mid-America | (7) | 7,343 |
| Atlantic | (8) | 3,717 |
| | Total | <hr/> 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