



STATE CANCER REGISTRIES AND ENVIRONMENTAL PUBLIC HEALTH TRACKING

Dennis Deapen, DrPH

Los Angeles Cancer Surveillance Program

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OVERVIEW



- ◆ Brief overview of state cancer registries including types of data reported and quality of the data.
- ◆ How can EPHT meet the needs of NAACCR and the State Cancer Registry staff?
- ◆ Identify any concerns that NAACCR/Cancer Registry has regarding the linkage of environmental data with cancer registry data.

WHAT IS NAAACCR?

- ◆ North American Association of Central Cancer Registries
- ◆ “Central” = population-based ~ states

North American Association of Central Cancer Registries



WHAT IS NAACCR?

- ◆ Established in 1987
- ◆ Organization of organizations interested in the development and application of cancer registration
- ◆ Four membership categories: full, sponsor, sustaining, individual

North American Association of Central Cancer Registries



NAACCR STRUCTURE

- ◆ Governed by elected Board of Directors
- ◆ IRB
- ◆ Various Ad Hoc Groups



WHAT IS NAAACCR?

13 Standing Committees:

- ◆ Bylaws
- ◆ Data Evaluation & Publication
- ◆ Data Use & Confidentiality
- ◆ Education
- ◆ Information & Technology
- ◆ Membership
- ◆ Program
- ◆ Public Relations
- ◆ Registry Certification
- ◆ Registry Operations
- ◆ Uniform Data Standards
- ◆ Web



RESOURCES

- ◆ Dues
- ◆ Sponsor contributions – many are in-kind
- ◆ CDC cooperative agreement – infrastructure
- ◆ NCI contract – cancer surveillance
- ◆ CDC contract – education
- ◆ NCI Conference grant



MISSION: AN ORGANIZATION TO ...

- ◆ ... develop and promote uniform data standards for cancer registration; provide education and training; certify population-based registries; aggregate and publish data from central cancer registries; and promote the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care **to reduce the burden of cancer in North America**



MAJOR ACTIVITIES

- ◆ Establish standards: definitions, codes, data exchange, publication, quality
- ◆ Train and educate registry staff
- ◆ Certify registries: assess quality
- ◆ Evaluate and publish data
- ◆ Promote use of registry data



CERTIFICATION

- ◆ Completeness of case ascertainment
- ◆ Completeness of key data elements
- ◆ Percent DCO cases
- ◆ Rate of Duplicate Cases
- ◆ Passing EDITS
- ◆ Timeliness



CERTIFICATION

- ◆ Level of Recognition: Gold or Silver
- ◆ Annual review
- ◆ Submit 2001 data file by December 2003
(within 23 months)
- ◆ Feedback
 - Achievement on all criteria
 - Certificate

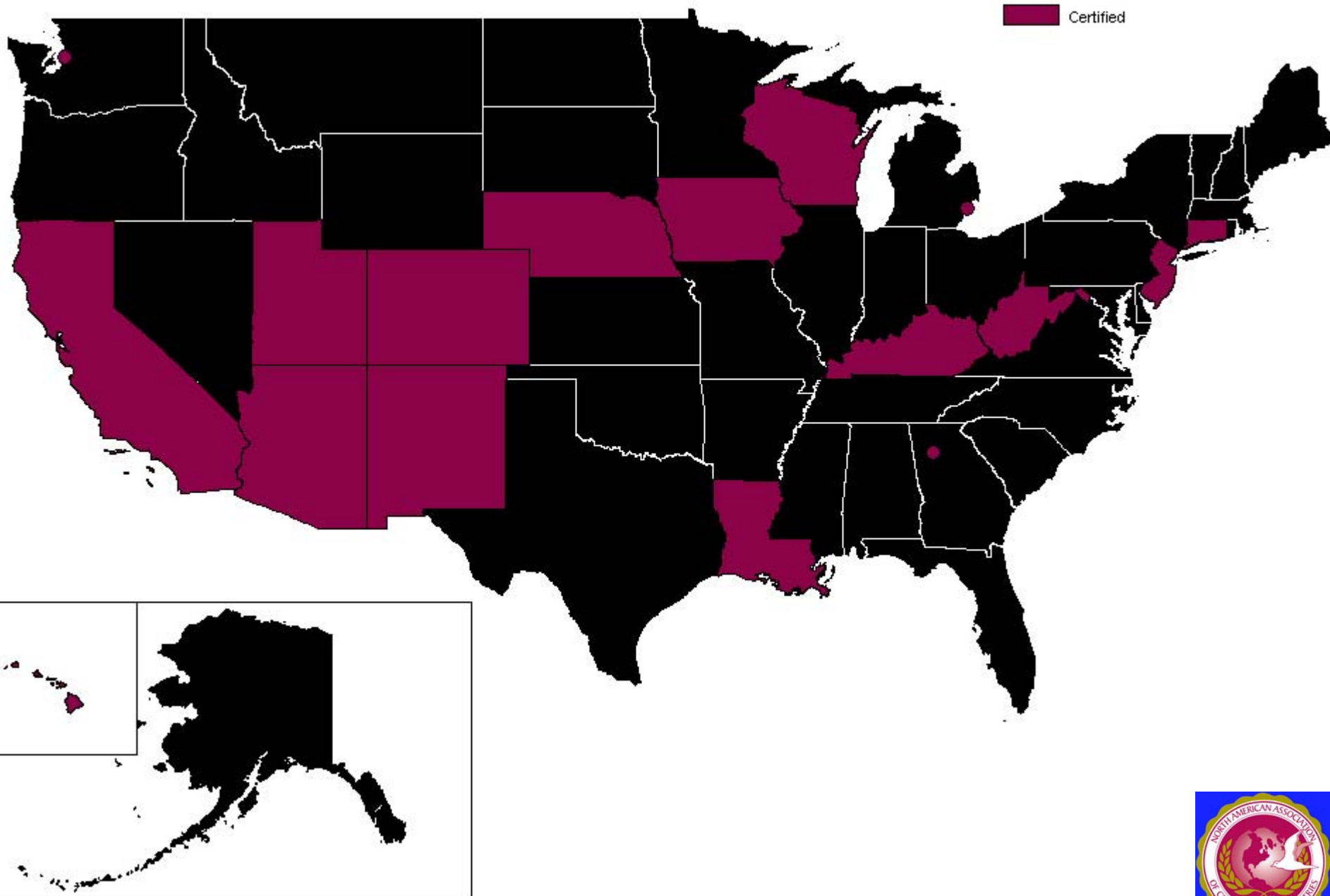


CERTIFICATION RESULTS OF 2000 DATA

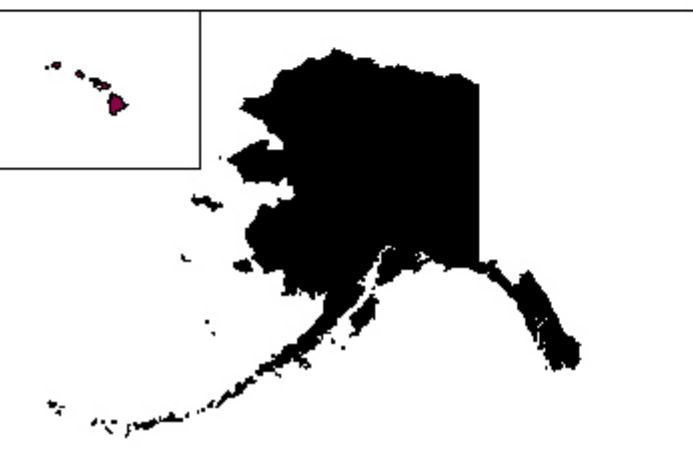
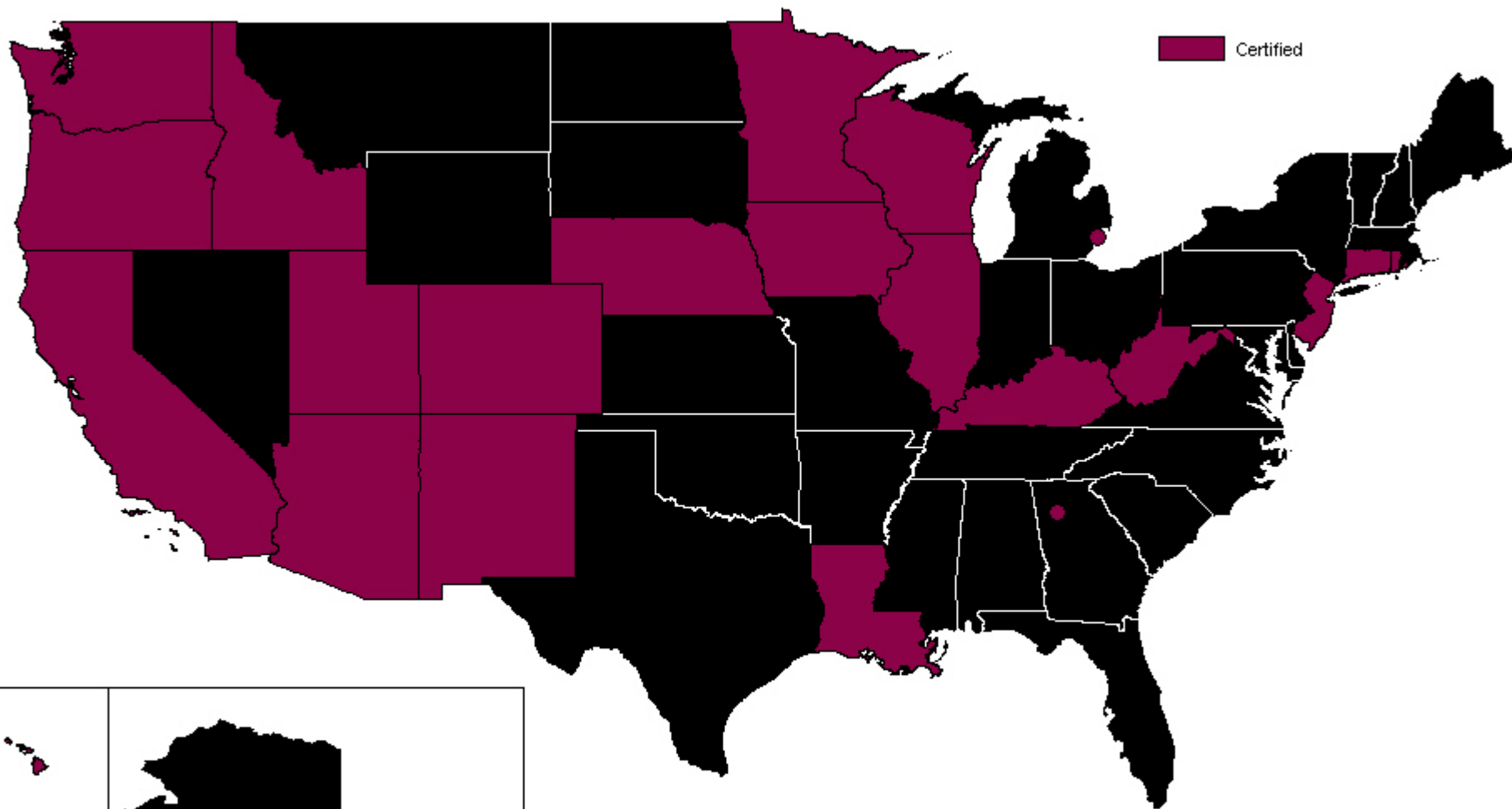
- ◆ 67 of 74 participated for 2000 data
 - 56 US; 10 Canadian
- ◆ For 2000, 60 registries were certified
- ◆ Certification Levels
 - 41 Gold
 - 19 Silver



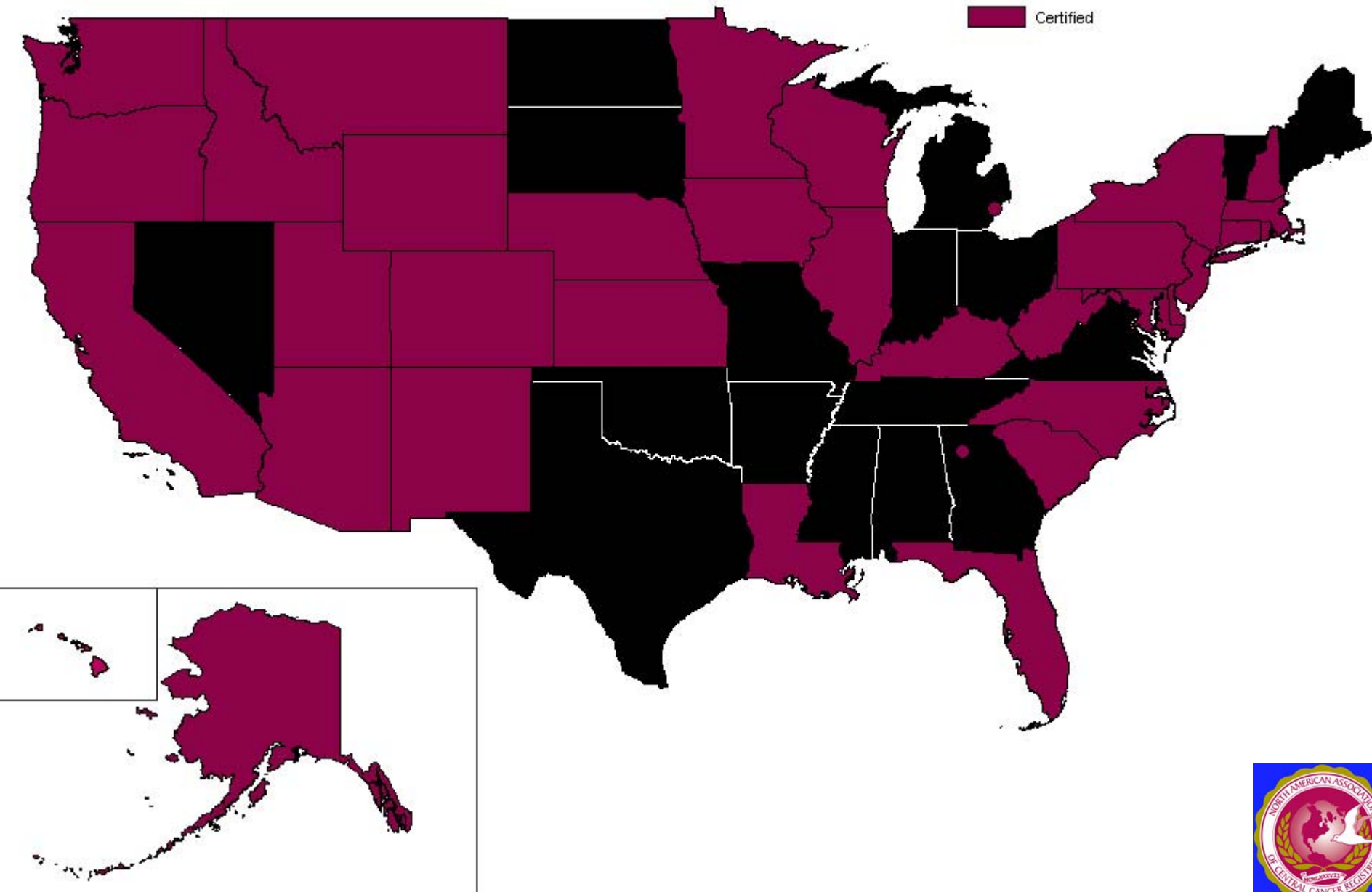
1995 US CERTIFICATION



1996 US CERTIFICATION

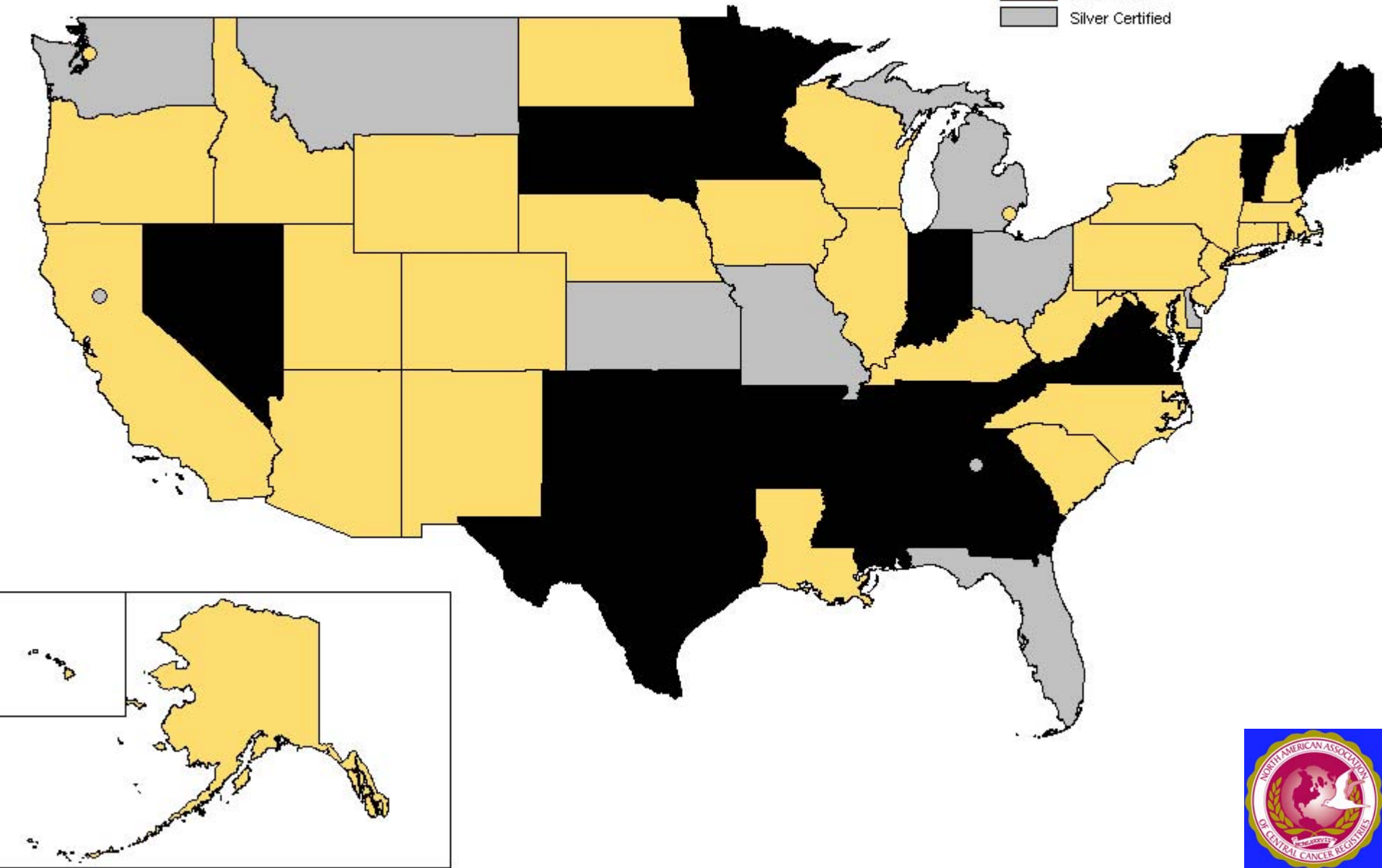


1997 US CERTIFICATION

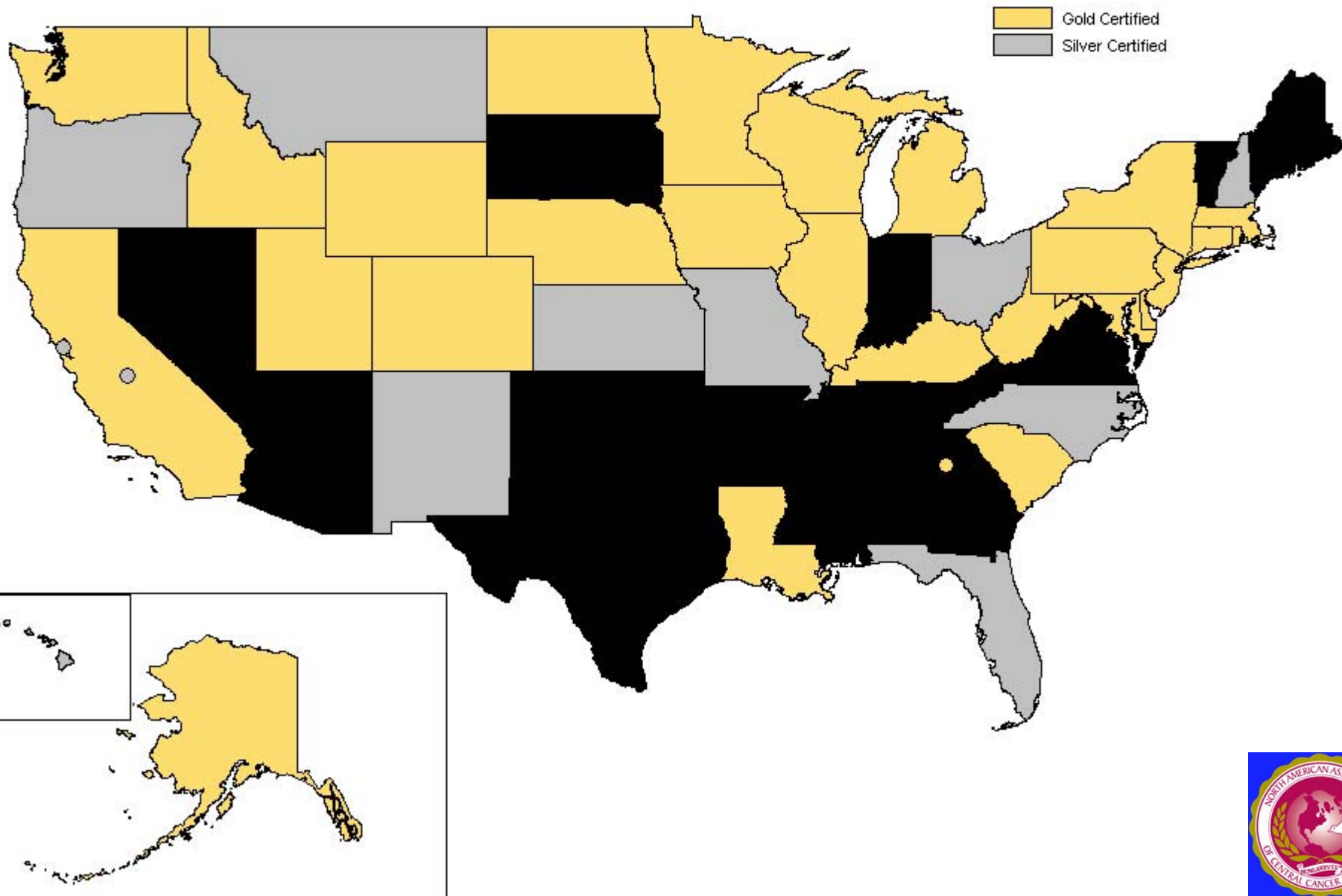


1998 US CERTIFICATION

Gold Certified
Silver Certified



1999 US CERTIFICATION



DATA USE FILES

- ◆ CINA: Cancer in North America
- ◆ PUBLIC USE: *CINA Plus* Online
 - Interactive online query system
- ◆ RESEARCH: *CINA Deluxe*
 - Data imbedded in SEER*Stat software using client-server platform
 - Discretionary Release



USE OF REGISTRY DATA

- ◆ Annual Report to the Nation
- ◆ ACS Cancer Facts & Figures
- ◆ Special analyses/monographs/manuscripts
- ◆ Data linkage studies*
- ◆ Patient contact studies*

*through individual registries

NAACCR

NAACCR, Inc.

2121 West White Oaks Dr

Springfield, IL 62704-6495

217.698.0800 (phone)

217.698.0188 (fax)

www.naacr.org 

NATIONAL PICTURE

- ◆ 50 state registries, plus some regional registries
- ◆ Substantial differences by
 - State regulations
 - Structure
 - Size
 - Years of experience
 - Research/health monitoring experience

NATIONAL PICTURE

- ◆ Funding of registries
 - State
 - CDC (National Program of Cancer Registries)
 - NCI (Surveillance, Epidemiology and End Results)
 - Research grants



TYPES OF DATA REPORTED



- ◆ Officially designated by states
- ◆ Strongly encouraged by NPCR and SEER
- ◆ NAACCR standard data set
- ◆ Local options

TYPES OF DATA REPORTED

- ◆ NAACCR standard
- ◆ Patient identifiers
 - Name
 - Address + census tract (geocoding optional)
 - Date of birth
 - Social security number
 - Race/ethnicity/birthplace
 - Occupation/industry
 - Socioeconomic status indicators (optional)



TYPES OF DATA REPORTED

- ◆ Descriptors of the cancer
 - Anatomic site/subsite/laterality/histology
 - Stage
- ◆ First course treatment
- ◆ Vital status follow-up (optional)

SUMMARY: REGISTRY DATA AND QUALITY

- ◆ Quality = timeliness, completeness, accuracy
- ◆ Variable, but improving
- ◆ Treatment sketchy, outpatient mostly missing

HOW CAN EPHT MEET THE NEEDS OF NAACCR AND THE STATE CANCER REGISTRIES?

- ◆ Each state is different
- ◆ General support
 - Provision of funding
 - Educating government and public
 - Public relations/communication skills & tools
- ◆ Specific to environmental issues
 - Technical support
 - Partnerships
 - Knowledge base

HOW CAN STATE CANCER REGISTRIES ASSIST ENVIRONMENTAL PUBLIC HEALTH TRACKING?

- ◆ Work to be performed by registry or outside investigator or both?
 - Small area (cluster) analyses
 - Studies of occupational groups
 - Population-based epidemiologic studies of environmental exposures
 - Other?

IDENTIFY CONCERNS REGARDING LINKAGE OF ENVIRONMENTAL DATA WITH CANCER REGISTRY DATA

- ◆ Confidentiality
 - addressable (although not all registries may have experience)
- ◆ Sound science vs. zealot activism
 - ecological fallacy = bad public health
- ◆ Registry and environmental experts public relations challenges
 - hiding results?
 - racist?

IDENTIFY CONCERNS REGARDING LINKAGE OF ENVIRONMENTAL DATA WITH CANCER REGISTRY DATA

- ◆ Reporting/complete file delay
 - Current best: >95% complete 14 months after calendar year, e.g., 2002 complete by March '04
 - Current worst: >95% complete 3-4 years after calendar year
 - Last reported cases are non-random, e.g. out patient diagnoses (melanoma, prostate, breast)
- ◆ Could be improved with additional resources
- ◆ Death data available sooner but cancer is underreported and not population-based

IDENTIFY CONCERNS REGARDING LINKAGE OF ENVIRONMENTAL DATA WITH CANCER REGISTRY DATA

- ◆ Pseudo electronic reporting

Electronically stored data



Manually extracted and entered into cancer
registry reporting software



Electronically submitted

IDENTIFY CONCERNS REGARDING LINKAGE OF ENVIRONMENTAL DATA WITH CANCER REGISTRY DATA

- ◆ True electronic reporting
 - Electronic casefinding of pathology report-based diagnoses implemented in several hospitals and labs
 - Myriad data systems in use
 - Insufficient demographic data included
- ◆ Efforts underway to develop full electronic reporting

IDENTIFY CONCERNS REGARDING LINKAGE OF ENVIRONMENTAL DATA WITH CANCER REGISTRY DATA

- ◆ Latency period
 - 5-40 years for most cancers
 - Registries only capture patient's address at dx, no length of residence
 - Makes registry-based environmental exposure studies very expensive
 - Risk both false positive and false negative results



IDENTIFY CONCERNS REGARDING LINKAGE OF ENVIRONMENTAL DATA WITH CANCER REGISTRY DATA

- ◆ National or multistate data (NAACCR, SEER, NPCR) are de-identified
- ◆ No multistate access/approval system

LOOKING TO THE FUTURE

- ◆ Share/build upon experience
 - NAACCR workshop Salt Lake City 6/11/04
- ◆ Build capacity
 - Faster, electronic reporting
- ◆ Identify challenges/lacking capacities