

Overview of Certification of Central Cancer Registries



Betsy A Kohler, MPH,CTR
Executive Director

North American Association of Central Cancer Registries (NAACCR)

October 9, 2013

American Immunization Registry Association
Denver Colorado




Topics to be Covered

- Overview of NAACCR and background on cancer surveillance
- Why NAACCR developed objective criteria (certification standards) to measure central cancer registry data quality (a historical perspective).
- Principles used to guide the development of certification standards.
- Implementation
- Participation
- Benefits
- Future Plans

North American Association of Central Cancer Registries

- Collaborative umbrella organization for
 - cancer registries (all in US and Canada)
 - governmental agencies (NCI, CDC, PHAC)
 - professional associations (ACS, ACoS, AJCC, CAP, CPAC, NCRA)
 - individuals interested in enhancing the quality and use of cancer registry data.

Mission

- promote uniform data standards for cancer registration;
- provide education and training;
- certify population-based registries; 
- aggregate and publish data from central cancer registries;
- 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.

Governance

- Governed by Board of Directors
 - Central registry directors, Sponsoring agency
- 8 full-time staff
- Most work done by committees of volunteers from member registries or organizations
- Funding through grants and contracts

Cancer Surveillance

- Systematic collection of cancer incidence and related data in a defined population
 - Standard definitions (cancer, multiple primaries)
 - Standard codes
 - Standard application of rules
- Cancer Surveillance is most sophisticated and complete disease surveillance system in North America

Types of Cancer Registries

Hospital /Central Cancer Registries

- Hospital Registry
 - Collects data on patients seen at their facility only
 - Not population based
- Central Cancer Registry
 - Collects data on all residents of an area (State, region, province)
 - Is population based
 - Compiles data from all sources
 - Obtains information from other states
 - Submissions come from hospitals and other sources

History

- Some hospital-based cancer registries, few population-based cancer registries prior to 1970s
- NCI SEER Program began 1973, 1970's many states started forming registries, 1990's Cancer Registry Amendment Act, NPCR-CDC Program
- Commission on Cancer had standards for hospitals
- New population-based registries forming, needed guidelines for comparability

Genesis of NAACCR Certification

- Representatives of central cancer registries and cancer surveillance organizations formed a voluntary collaboration – NAACCR
- Volunteers collaborated to establish common definitions, data collection methods, and standard procedures
- Establish standard for submitting data in common format
- Wanted an external validation of quality of data and confidence in data to aggregate across states

Four Principles were Used to guide the Development of Certification Standards for Central Cancer Registries

1. Certification Standards should be objective
2. Certification standards should focus on the product of the central cancer registries
3. The certification process should provide confidential feedback to help individual registries identify their strengths and weaknesses
4. Certification should provide the basis for recognizing central registries that have demonstrated excellence in the areas of completeness, accuracy and timeliness

Other Guiding Principles

- All NAACCR member registries should be able to reach the certification standards.
- Certification standards should represent criteria that would allow data from different registries to be aggregated for the purpose of defining the burden of cancer by age, sex, race and sub-geographic region.
- Certification standards should be relatively stable and not something that changes frequently to create distinctions between registries.
- NAACCR should strive to help all member registries meet certification standards.

Developed Metrics

- Established committee of Registry Directors and experts to develop quantitative and objective measures
- When measuring “the unknown” the method must have an internal logic
- All of the major underlying assumptions must be specified
- When all of the assumptions are controlled or accounted for, what remains can be assumed to be a reasonable estimate of the unknown

Developing metrics - continued

- Involved the community
- Allowed time for discussion, education, implementation
- Beta testing of measures, submission process

Dimensions of Central Cancer Registry

Data Quality

- Completeness of case ascertainment
- Completeness of information collected on critical variables
- Accuracy of the data collected
- Timeliness of the data

NAACCR Certification Criteria

- Completeness of case ascertainment
 - 95% for gold
 - 90% for silver
- Passing EDITS and inter-record EDITS
 - 100% for gold
 - 97% for silver
- Percent DCO cases
 - $\leq 3\%$ for gold
 - $\leq 5\%$ for silver



NAACCR Certification Criteria

- Timeliness
 - Within 23 months
- Rate of duplicate cases
 - $\leq 1/1,000$ for gold
 - $\leq 2/1,000$ for silver
- Missing data field
 - Sex, age, county
 - $\leq 2\%$ for gold
 - $\leq 3\%$ for silver
 - Race
 - $\leq 3\%$ for gold
 - $\leq 5\%$ for silver

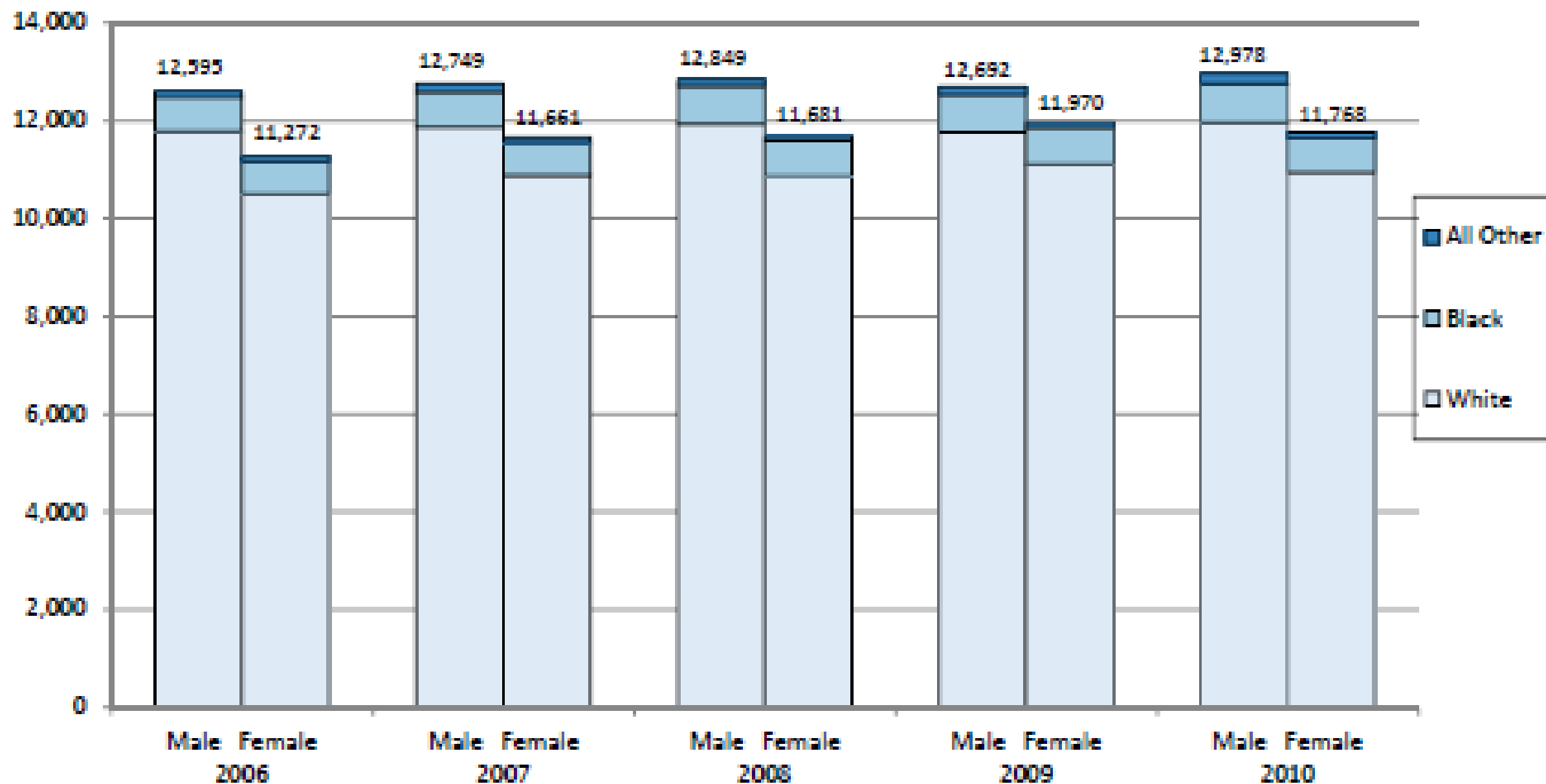
Kentucky Cancer Registry

**NAACCR
Registry Certification on Quality, Completeness & Timeliness of 2005 Data
Summary of Certification Measures**

Registry Element	Gold Standard	Silver Standard	Actual Measure*	Measurement Error Allowed	Standard Achieved
1. Completeness of case ascertainment	95%	90%	105.4%	1.0%	Gold
2. Completeness of information recorded <ul style="list-style-type: none">▶ Missing/unknown “age at diagnosis”▶ Missing/unknown “sex”▶ Missing/unknown “race”▶ Missing/unknown “State/Province & county”	<div><=2%</div>	<div><=3%</div>	<div>0.0%</div>	<div>-0.4%</div>	Gold
	<=2%	<=3%	0.0%	-0.4%	Gold
	<=3%	<=5%	1.2%	-0.4%	Gold
	<=2%	<=3%	0.0%	-0.4%	Gold
3. Death certificate only cases	<=3%	<=5%	1.0%	-0.4%	Gold
4. Duplicate primary cases	<=1 per 1000	<=2 per 1000	0.1 per 1000	-0.4 per 1000	Gold
5. Passing EDITS	100%	97%	100.0%	Not applicable	Gold
6. Timeliness	Data submitted within 23 months of close of accession year.				Gold
Certification Status					Gold

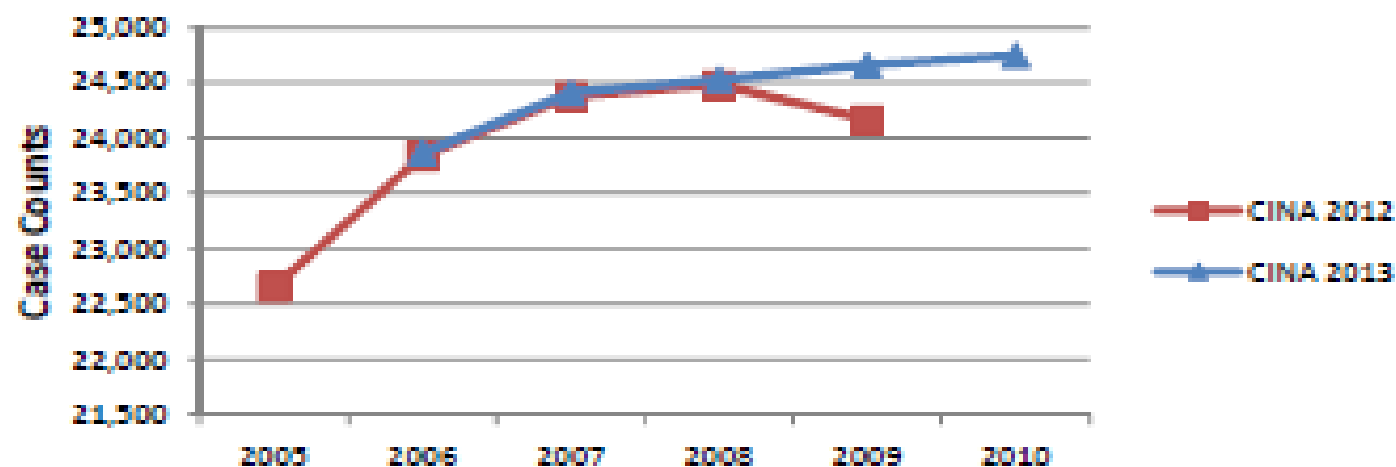
* Measures are truncated to one decimal place. The measure for completeness of case ascertainment includes an adjustment for unresolved duplicates.

Case Counts (Malignant, Inc. In Situ Bladder), CINA 2006-2010 by Gender, Race and Year of Diagnosis



All Other Race includes American Indian/Alaska Native, Asian, Pacific Islander, Other/Unknown

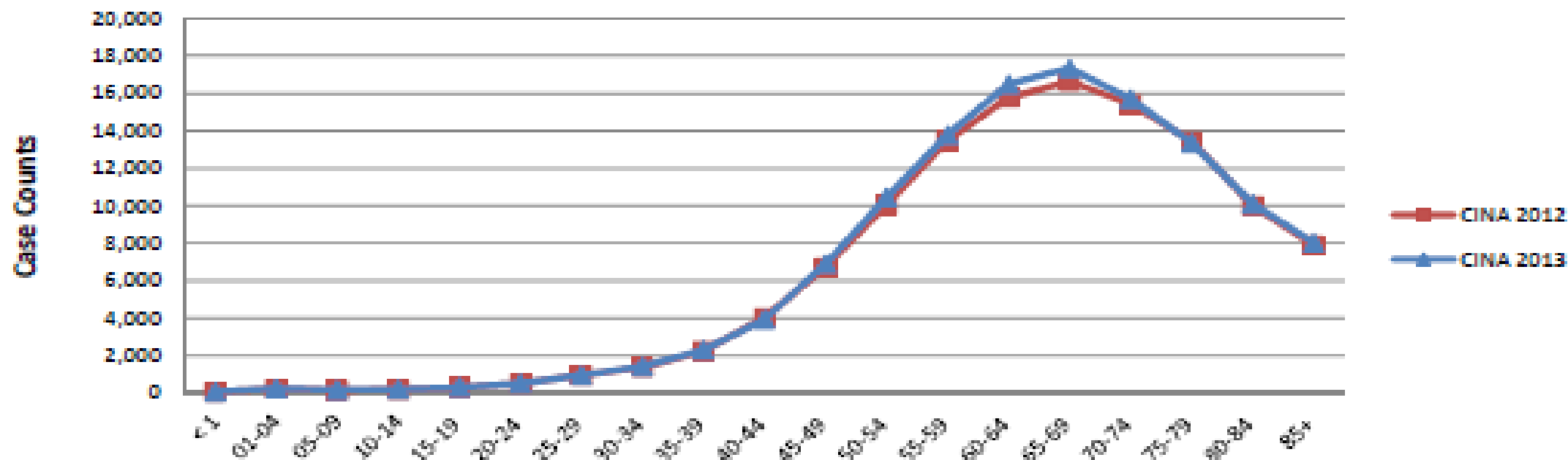
Overall Counts by Year of Diagnosis



Overall Counts by Year of Diagnosis

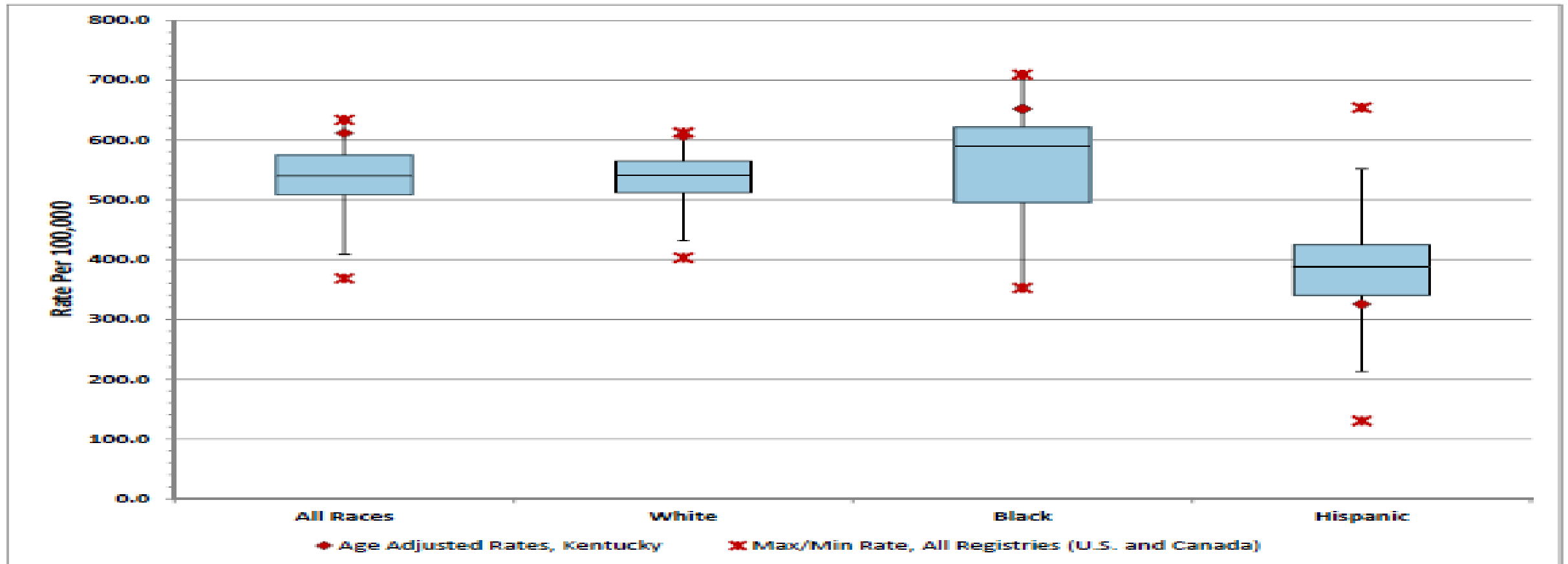
	CINA 2012	CINA 2013	% Change
2005	22,653	NA	N/A
2006	23,839	23,867	0.12%
2007	24,378	24,410	0.13%
2008	24,481	24,530	0.20%
2009	24,164	24,662	2.06%
2010	NA	24,746	N/A
Total	119,515	122,215	2.26%

Case Counts by Age at Diagnosis



Comparison of Rates* (2006-2010) by Cancer Site, Gender and Race/Ethnicity

All Sites (Malignant), Males



Rates and Counts, Kentucky				
	All races	White**	Black**	Hispanic**
Rate	611.2	606.8	651.7	325.4
Count	63,863	59,329	3,730	348
Rate Percentile	98.5%	98.1%	88.8%	20.3%

Note: ~ indicates no data available; ^ indicates fewer than 6 cases; shading indicates rate is outside 25-75% Percentile Range (IQR)

Rate Statistics For All Submitting Registries (U.S. and Canada)				
	All races	White**	Black**	Hispanic**
25-75% Percentile (IQR)	507.8 - 574.1	511.6 - 564.8	495.1 - 621.0	339.7 - 424.4
Minimum-Maximum Range	368.3 - 633.3	402.9 - 612.0	352.4 - 709.4	130.2 - 653.9
Median	539.8	540.4	588.9	388.1
Upper Whisker Range	574.1 <- 633.3	564.8 <- 612.0	621.0 <- 709.4	424.4 <- 551.5
Lower Whisker Range	408.4 -< 507.8	431.8 -< 511.6	352.4 -< 495.1	212.7 -< 339.7

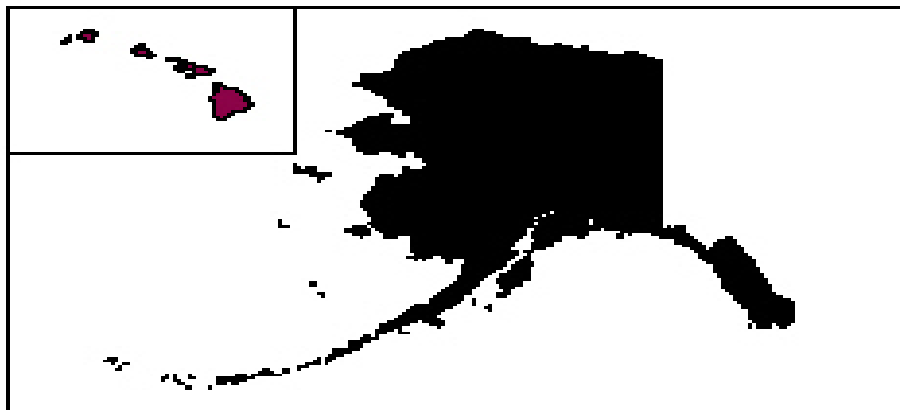
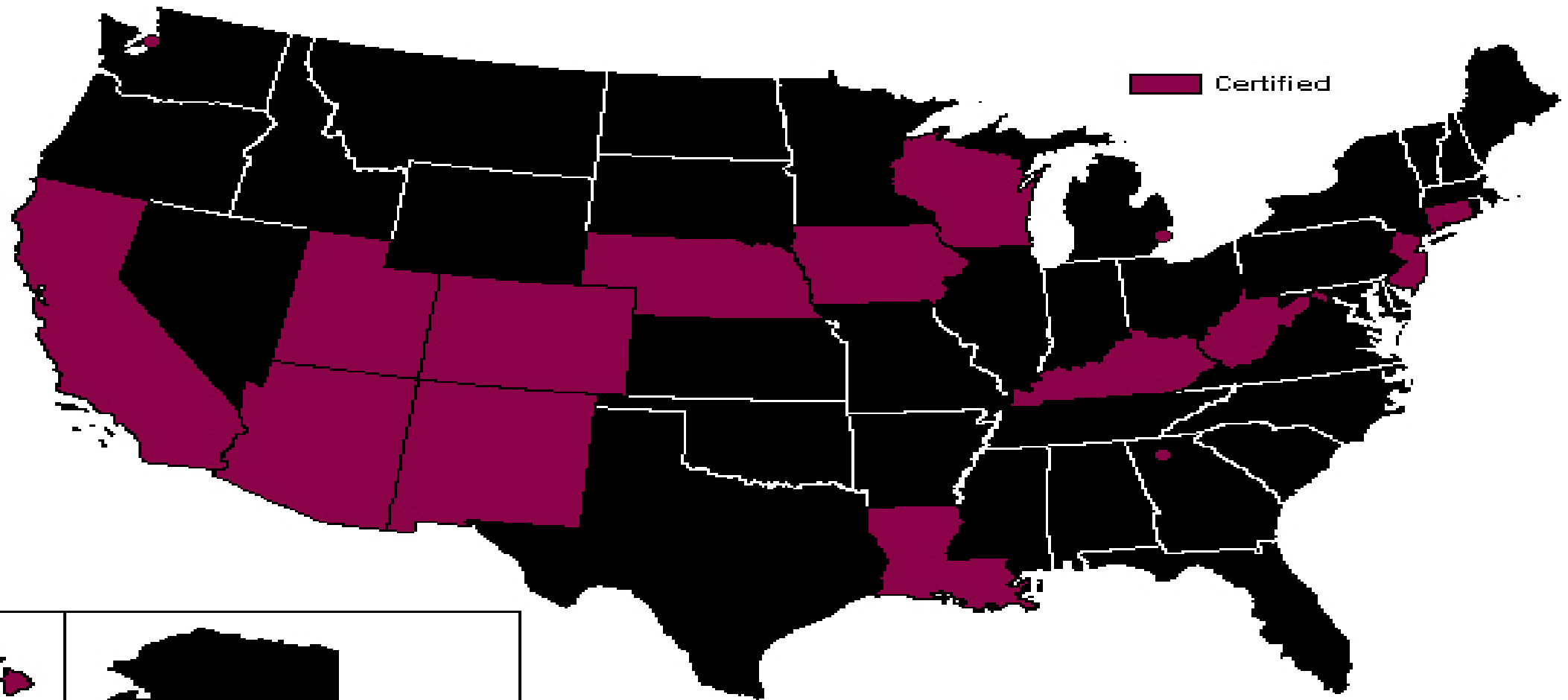
*Rates are per 100,000 population and are age-adjusted by five-year age groups to the 2000 U.S. standard population based on single years of age.

Implementation

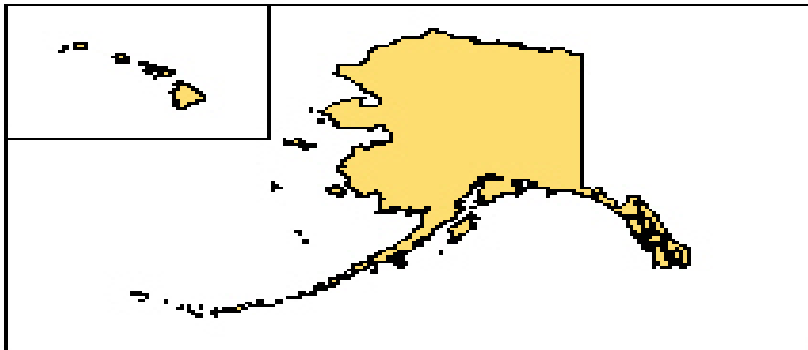
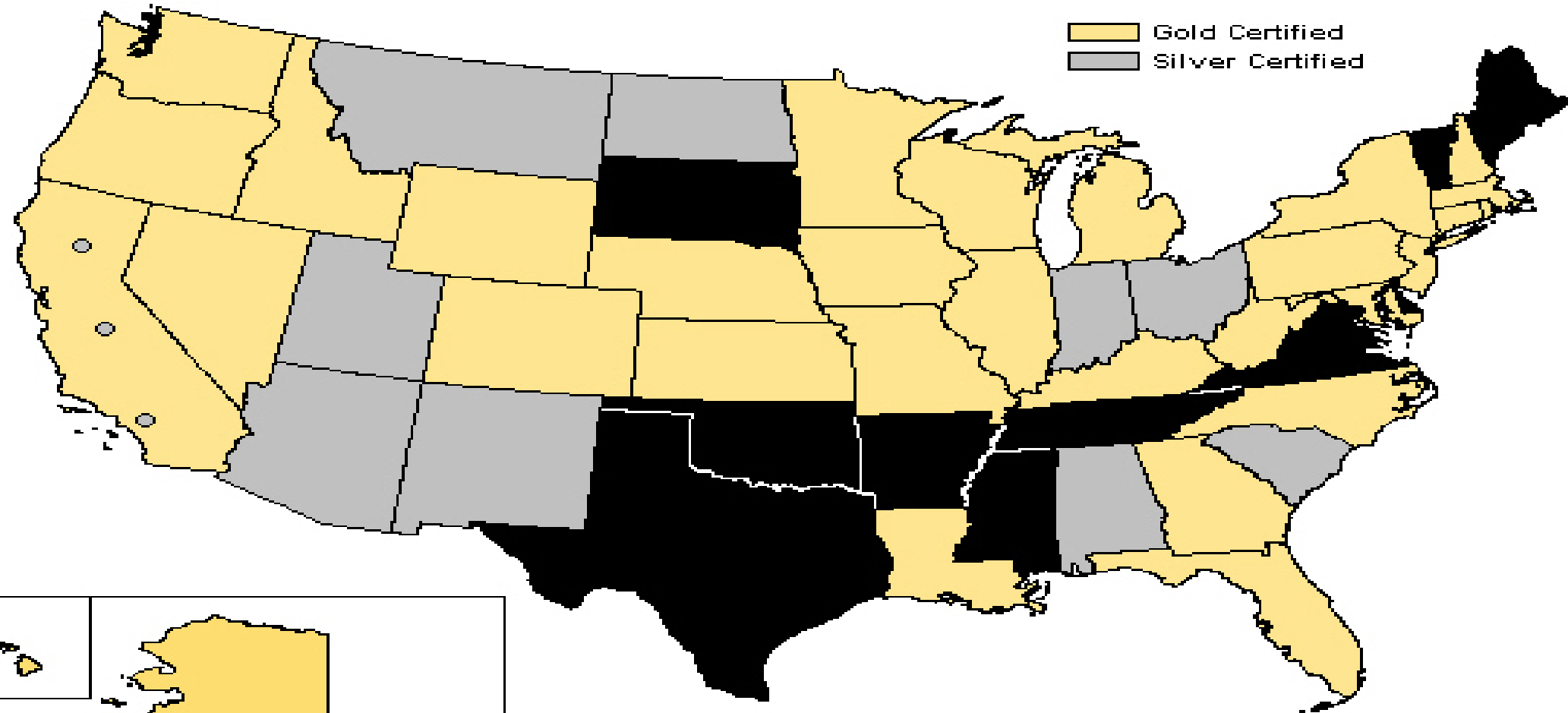
- Establish standards that were attainable, yet meaningful
- Face Validity
- Voluntary process
- Incentives:
 - External, objective process
 - Publication in ***Cancer in North America***
 - Use data in combined rates for US/Canada
 - Recognition at Annual Conference



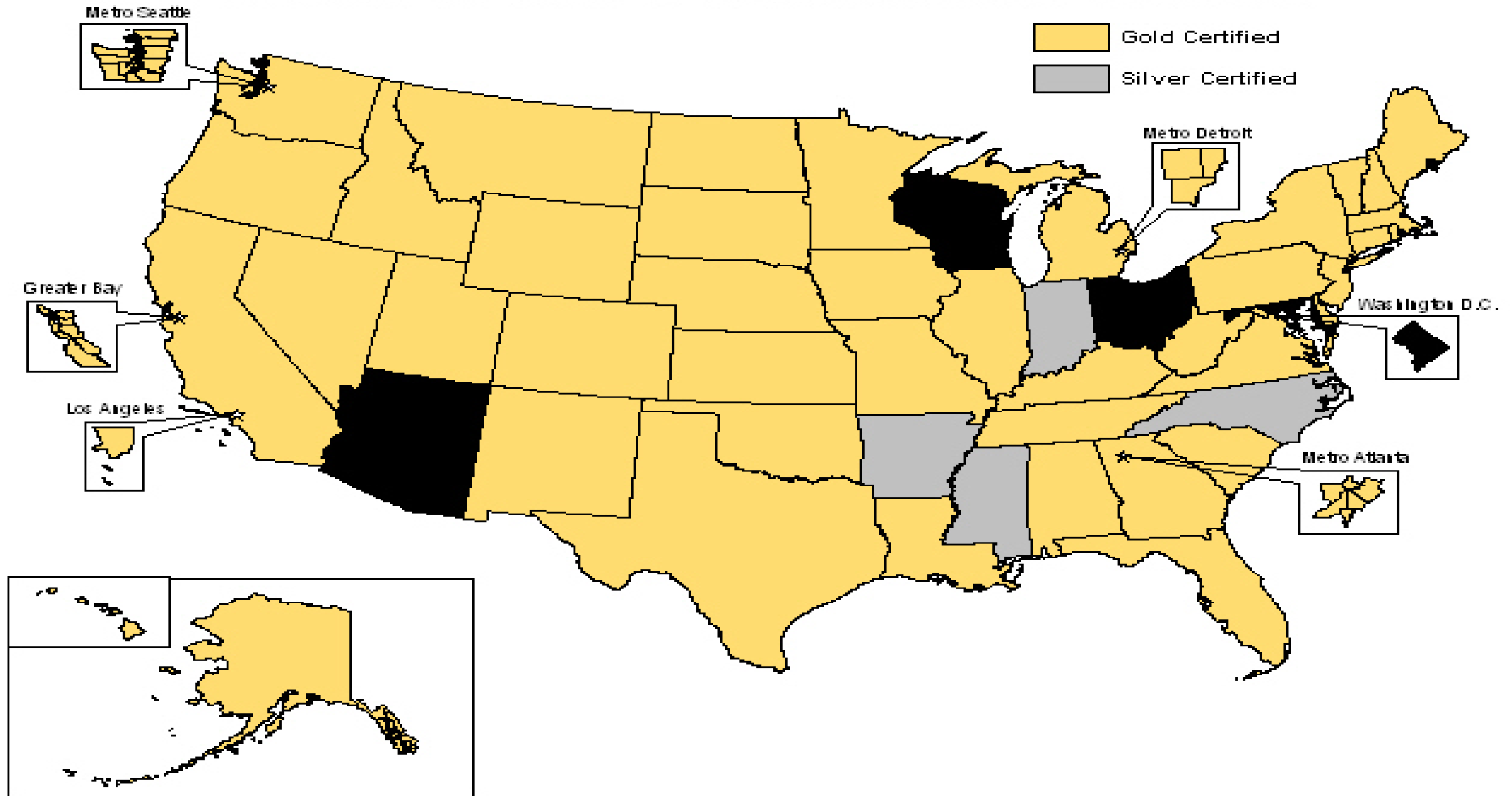
CERTIFICATION STATUS OF NAACCR US CANCER REGISTRIES FOR 1995 DATA



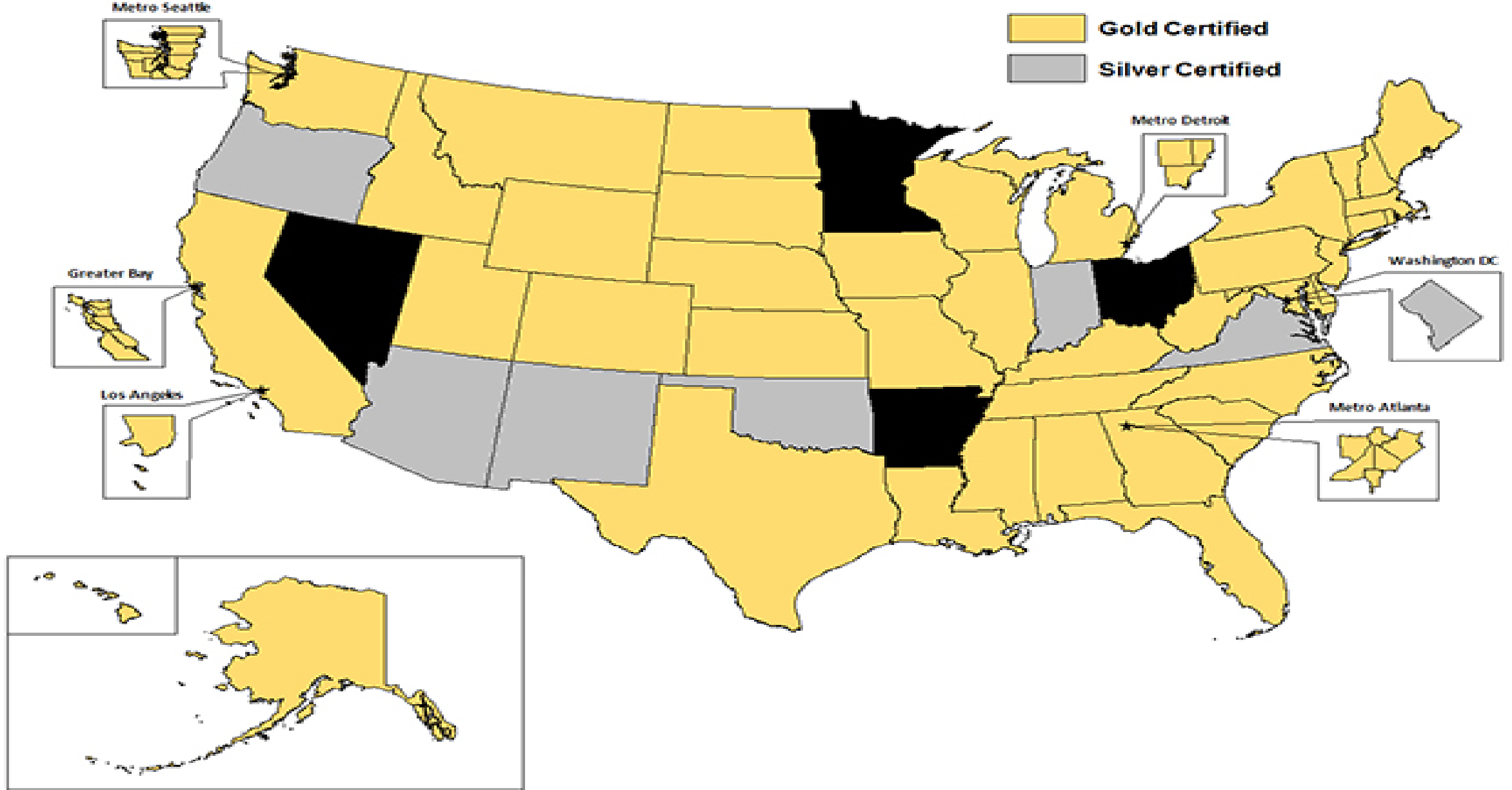
GOLD AND SILVER LEVEL CERTIFICATION STATUS OF NAACCR US CANCER REGISTRIES FOR 2000 DATA



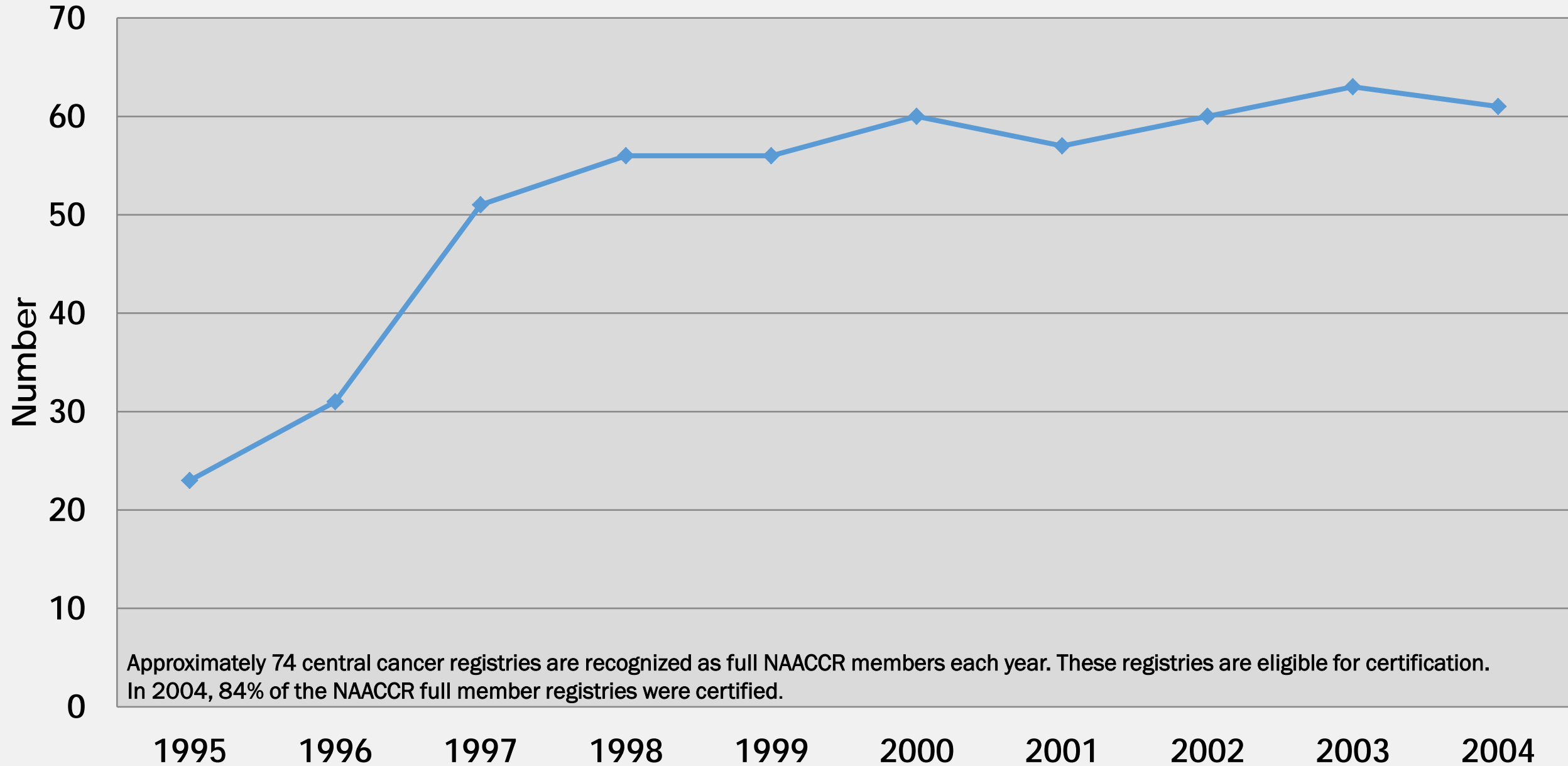
GOLD AND SILVER LEVEL CERTIFICATION STATUS OF NAACCR US CANCER REGISTRIES FOR 2005 DATA



Gold and Silver Level Certification Status of NAACCR U.S. Cancer Registries for 2010 Data



Number of Central Cancer Registries Receiving NAACCR Certification (by year)



Summary and Conclusions

- Registries that have collected data from all sources, included cases not previously reported that died of cancer, conducted data exchange with other states/provinces, and reconciled edit errors within 22 months of the close of an accession year have nearly always met the criteria for NAACCR certification.
- The number of registries able to meet the NAACCR certification standards has increased dramatically over time.
- The NAACCR certification process has helped registries to obtain additional resources.
- The NAACCR certification process has made it possible to aggregate central cancer registry data across geopolitical boundaries.

Other Benefits

- Dramatic improvement in data quality across North America
- Use of NAACCR Data in the “Annual Report to the Nation”
- Use of NAACCR Data in developing better cancer incidence projection models
- Increasing use of surveillance data for research, cancer control evaluation, and policy decisions

Other Benefits (Cont.)

- Improved understanding of data aggregation issues
- Improved measures of cancer incidence and more reliable comparison data
- Demonstration of “Return on Investment” for federal funds supporting our work
- More confidence in the comparability of North American data

Next Steps

- Continue to assess and improve our metrics.
- Consider developing criteria for specialized certification (research, cancer control, basic surveillance)
- Offer certification services to registries beyond North America

Questions?



Betsy Kohler
bkohler@naaccr.org

Thank You!

