

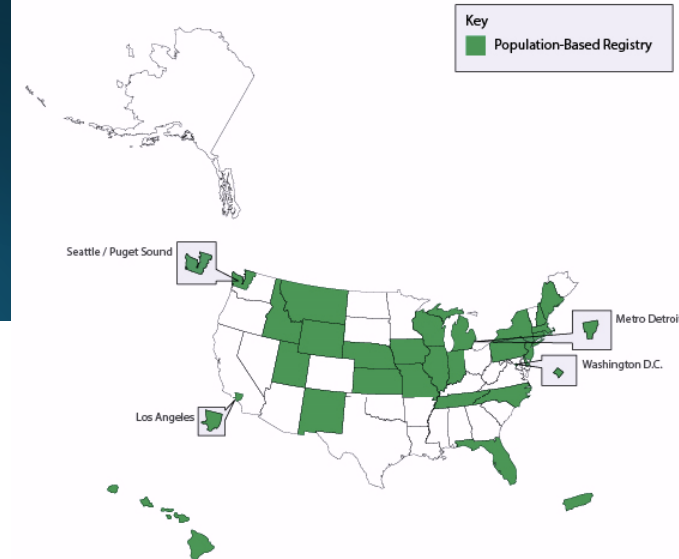
# Perspective: North American Association of Central Cancer Registries

Betsy Kohler, MPH, Executive Director

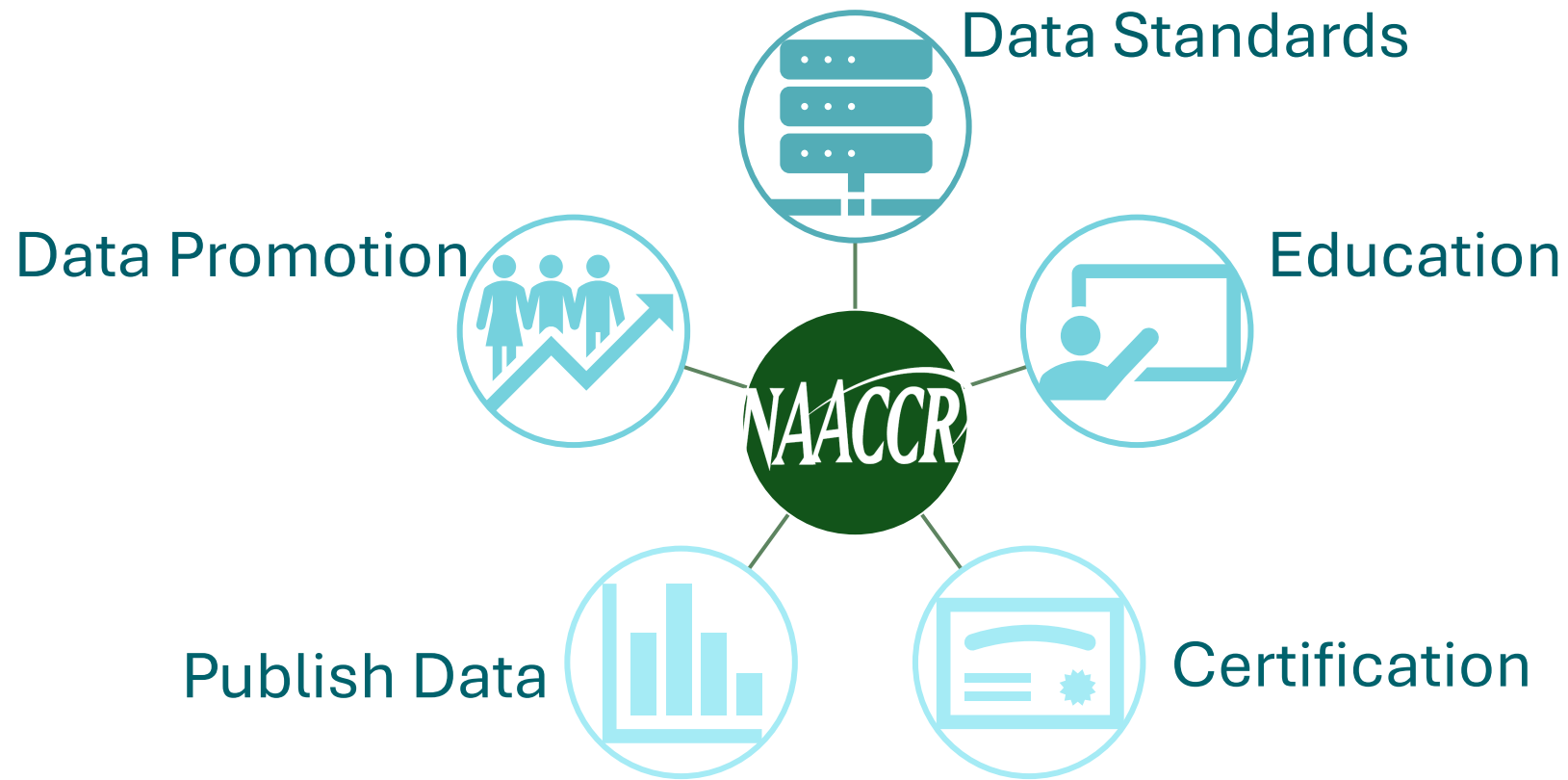
North American Association of Central Cancer Registries

# History

- Many population-based cancer registries forming in states during late 1970's and early 1980's
- No uniform data standards in place
- Data aggregation on a regional or national level was limited
- Late 80's: convened to develop standards
  - All central cancer registries in US
  - Governmental agencies (NCI, CDC)
  - Professional associations (ACS, ACoS, AJCC, NCRA)
- NAACCR convening body to develop consensus standards for data and data exchange, registry training and certification
  - Expanded to include Canadian Registries and organizations (Canada, US)



# NAACCR's Mission





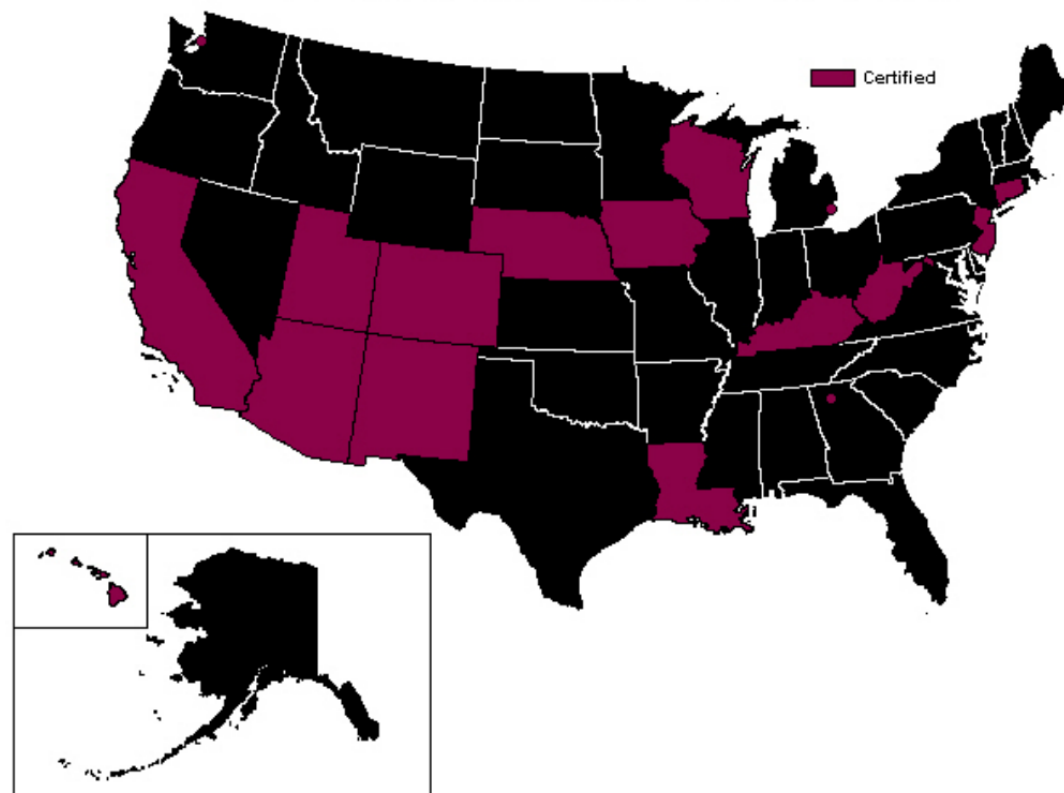
# NAACCR: Central Cancer Registry Certification

- + • **Purpose:** Provide **INDEPENDENT** assessment of data quality and set the bar on high quality cancer surveillance data.
- • Necessary step to **aggregate** data across US– **NAACCR** first to do so
- **Ensures comparability**
- Based on **completeness, timeliness, and quality** of reporting
- Registries use to advocate for **resources** and data users to know **reliability** of data
- Only system of its kind internationally with **objective and measurable** criteria

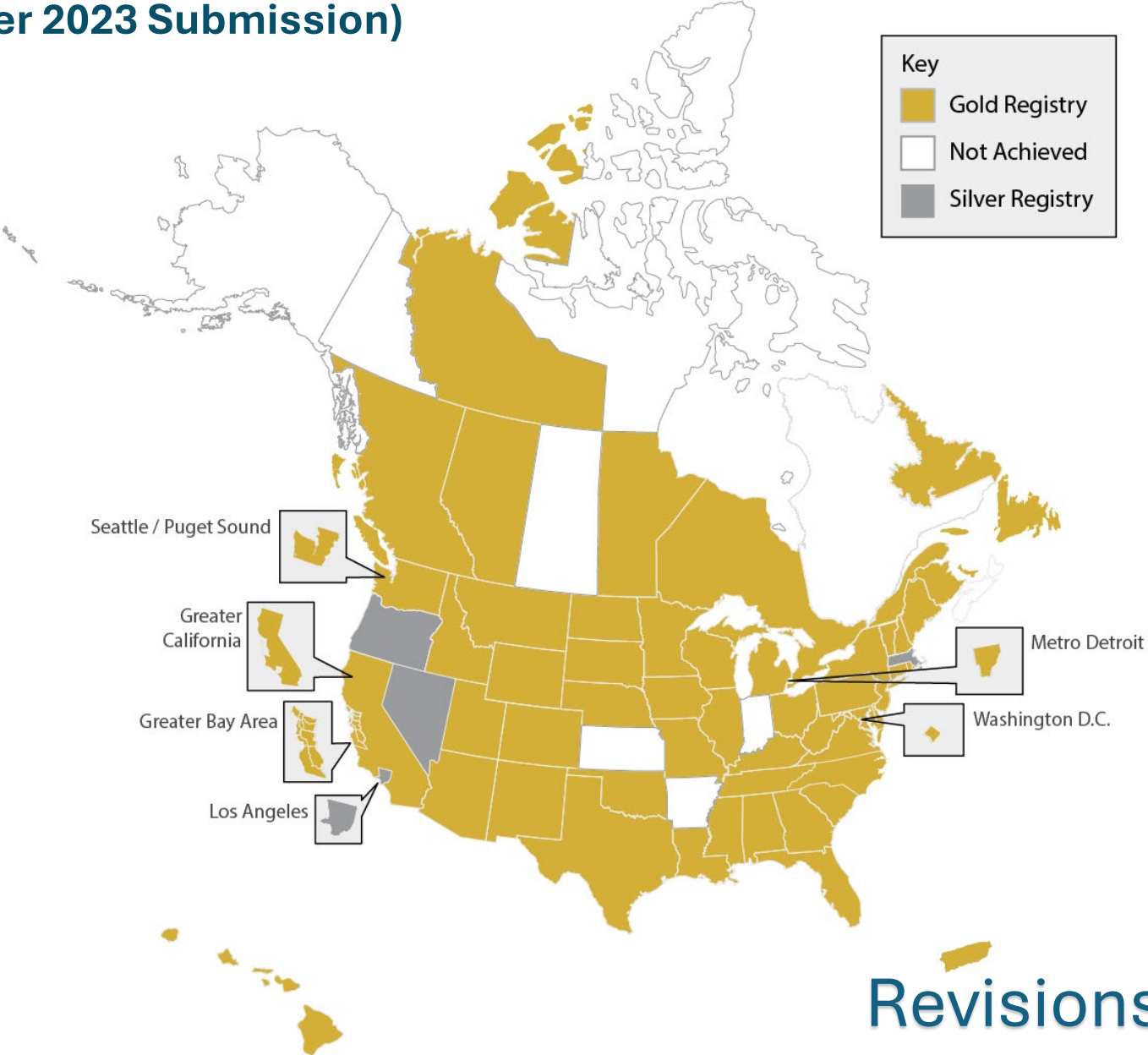
## U.S. Registries Certified in 1998 for 1995 Incidence Data

**1998  
Certification  
for  
Diagnosis  
Year 1995**


CERTIFICATION STATUS OF NAACCR  
US CANCER REGISTRIES FOR 1995 DATA



2024 Certification for Diagnosis Year 2021  
(based on December 2023 Submission)







# Collaborative Efforts to Support and Advance Cancer Surveillance

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# NAACCR: Cancer Surveillance Standards

- Data standards developed with all partners engaged to ensure:
  - Consistent, cost-effective implementation on population level
  - Comparable data across US and Canada in clinical and central registries
- Updated annually
- All changes based on diagnosis year



# Coordination & Strategic Planning – Multi-Agency Priorities

## Mid-Level Tactical Group

- Oversees collaborative change management for data standards
- Develops implementation strategy for complex changes
- Includes all cancer registry standard-setters + other stakeholders
- Meets at least monthly

## High-Level Strategic Group

- Ensures high-level collaborative decision-making
- Promotes and supports shared initiatives and inter-agency strategic planning
- Includes all cancer registry standard-setters + other stakeholders
- Meets every other month

# MLTG Change Management & Implementation

1.

## Change request submitted

Changes are proposed or sponsored by standard-setting agencies and may include:

- New data item(s)
- New codes for existing data item(s)
- New SSDI schema(s)

2.

## MLTG reviews request

The Mid-Level Tactical Group reviews the request to ensure its validity and justification

3.

## Technical review & feasibility testing

- UDS WG reviews proposed codes & definitions
- Feasibility testing is performed by requesting agency
- UDS works with requestor to finalize codes & definitions

4.

## MLTG Votes

MLTG reviews results of feasibility test and technical review and makes recommendations to HLSG



5.

## HLSG Votes

High-Level Strategic Group makes final determination on implementation. Changes that are not approved are sent back to requestor for reconsideration

6.

## Data Dictionary

UDS WG incorporates new data item, definition, and codes into the data dictionary. Standard-setters submit updates for Required Status table.



7.

## Implementation Guidelines

The Implementation Guidelines Task Force writes recommendations for registries and software vendors to incorporate the changes



8.

## Edits Metafile(s)

The Edits WG updates the metafiles to include the new/revised data item



9.

## Software Development

- APIs updated
- Vendors program changes into registry software and issues updates to registries



10.

## Training Materials

Standard-setters develop training materials, webinars and workshops to help registrars understand and implement the changes



11.

## Deployment

Cancer Registrars throughout North America begin collecting the new data item in a standardized format.



## Work Groups

The Uniform Data Standards (UDS) and the Edits Work Groups are subgroups of the NAACCR

Standardization & Registry Development Steering Committee and include representatives from registries, software vendors, and standard-setters.

## Members of the MLTG & HLSG



# Visioning the Registry of the Future

- Periodically convene partners to focus on how registries will function in future
- Electronic pathology data
- US health IT standards
- Engaged in USCDI+ Cancer Registry and HL7 standards development and feedback
- Educate membership
- Host advisory group with informaticists from NCI-designated cancer centers

# Opportunities

- Collaboratively built the most reliable, respected disease surveillance system in the US/world
- Data are high-quality and widely used- VALUED
- Well-trained, knowledgeable, committed work force
- Automation of central registries processes key to realize advances in technology
- Partnerships with HL7, mCODE, ONC are emerging to advance data collection and improve real-time reporting

# Challenges

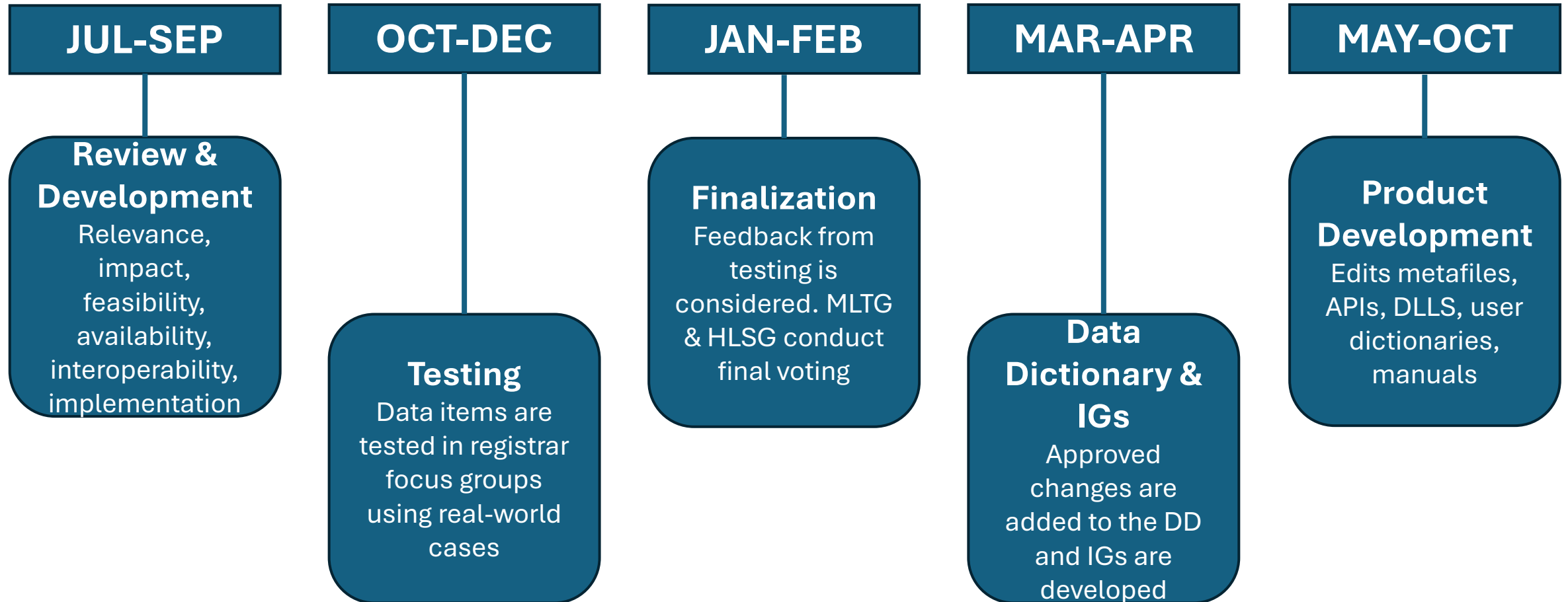
- Inherent complexity in curating a high-quality cancer incidence record from many sources
- Data systems developed in the 70's and 80's make real time data reporting a significant challenge for most registries
  - Early-capture data may be biased and inaccurate
- Registries under-resourced to meet increased demands & promote use of data—funding issues
- Incentives/penalties required to ensure implementation of EHR data collection
- Many state policies inhibit wide-spread data sharing from central registries.

# Thank you

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# Change Management Timeline



# NAACCR Certification Criteria

Standard	Silver	Gold	NJSCR
Timeliness	Within 23 months of diagnosis		Gold
Completeness	95%	90%	Gold
Pass EDITS	100%	97%	Gold
% Death Certificate Only	< 3%	< 5%	Gold
Duplicate Rate	< 1/1,000	< 2/1,000	Gold
Missing sex, age, county	< 2%	< 3%	Gold
Race	< 3%	< 5%	Gold

