Cancer Surveillance: A CiNA (Cancer in North America) Perspective

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Presentation Overview

- NAACCR Call for Data & Certification
- What is CiNA?
  - CiNA Data Products
- Some challenges to calculating cancer statistics
  - Demographic
  - 2020 cancer burden

Personal note

NAACCR…

- What does it stand for anyway?

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What is NAACCR?

- NAACCR pronounced “Nay-Sir”
  - North American Association of Central Cancer Registries
  - US and CAN (yeah, Mexico is North American but ☹)
- Standard setter (but not a funder)
- Umbrella organization
  - Infrastructure for collaboration and support of central cancer registries and cancer surveillance – greatest strength is our members
  - Martha’s question about sex codes

NAACCR Call for Data & Certification

- Processes that central registries are expected to perform
  - Death Clearance, Deduplication, Geocoding
- Define process for evaluation
  - NAACCR Certification, CiNA Evaluation
    - Completeness, Quality, Timeliness

NAACCR Call for Data (CFD) Overview

- Focus on NAACCR CFD https://www.naaccr.org/call-for-data/
  - Oregon also participates in NPCR/CDC CFD
  - Coordinated but separate submissions
- NAACCR CFD
  - Primary Goal – NAACCR Certification (Single year, 2021)
  - Secondary Goal – CiNA statistics (Multiple years, 1995-2021)
    - Cancer in North America (CiNA)
    - Produce US, Canada, and State-specific statistics
      - Incidence, survival, prevalence, trends, Annual Report to Nation, ACS F&F, delayed rates
  - Tertiary Goal – National-level research
    - CiNA Research datasets
    - Support NAACCR approved research (internal and external researchers)

NAACCR Call for Data (CFD) vs NCDB

- Some aspects are similar to the ACS/NCDB CFD
  - Annual (Nov/Dec vs Mar), submission portal, NAACCR layout, .xml, 24 months
  - Set case selection criteria, select variables
  - Case Ascertainment/Completeness is evaluated
    - "frantic search for cases" – multiple reporting sources
  - Edits—100% resolution

NAACCR Call for Data (CFD) Preprocessing

- Prior to creation of submission file
  - Case ascertainment (population-based)
    - Death Clearance
    - Physician office reporting, pathology reports
  - Deduplication
    - Updated protocol
    - Match*Pro
  - Geocoding
    - Patient address

NAACCR Call for Data (CFD) Preprocessing 2

- Death Clearance
  - NAACCR Certification Criteria
  - One of many efforts toward complete case ascertainment
    - Minimum requirements updated 2023 https://www.naaccr.org/wp-content/uploads/2023/05/NAACCR_Death-Clearance_Manual-4-23-FINAL.pdf
- Link database to mortality records
  - Append death information (date, cause) to cancer record
  - Identify missed cases
- Follow-back to hospitals and physicians to move "DCO" to higher quality case, more complete information

NAACCR call for data (CFD) Preprocessing 3

- Deduplication
  - NAACCR Certification Criteria
  - Patient-level
    - Protocol updated last year—significant effort
    - 100% resolution all years of data (1995-2021)
  - Tumor-level
    - Protocol update this year—significant effort
    - Role out to manage the burden

NAACCR call for data (CFD) Preprocessing 4

- Geocoding
  - Manual effort (extract, upload, process, download, reimport)
  - "spatially enable" cancer data – geocoding based on patient address at diagnosis
    - Quality of incoming address data greatly influences geocoding burden
- Geocoded data
  - NAACCR Certification Criteria (County at Diagnosis—Analysis, derived field, NAACCR Item #89)
  - Supports county-level surveillance, cancer cluster investigations, small area research, hospital catchment area analysis, health equity research, health disparities research, geospatial epidemiology

NAACCR Call for Data (CFD) submission file

- Create submission file
  - Cases consolidated from all reporting sources
- Run and resolve edits
  - Regular edits AND inter-record edits
- Create output file using the tool
  - Creates packaged .xml submission file
  - Derives calculated fields (e.g., survival variables, NAACCR poverty code)
  - Deletes PHI and non-required variables
- Submit file
  - 24 month for Certification, 12 month for evaluation, 1995+ for CiNA research

NAACCR Call for Data (CFD) Post-Submission

- Submission Forms & Signed Documents
  - Details on submission – counts, processes, etc
  - Data Assurance Agreement
  - Consent for On-going CiNA Research
    - ACS Facts & Figures, MTC postmarket surveillance (FDA requirement), CiNA Public Use Dataset, American Lung Association Annual Report, Delay Adjustment Modeling, Impact of Affordable Care Act on Cancer Stage at Diagnosis
- CaRI – Cancer Researcher Information DB
- Special projects submissions (VPR, NCCR)

NAACCR Certification

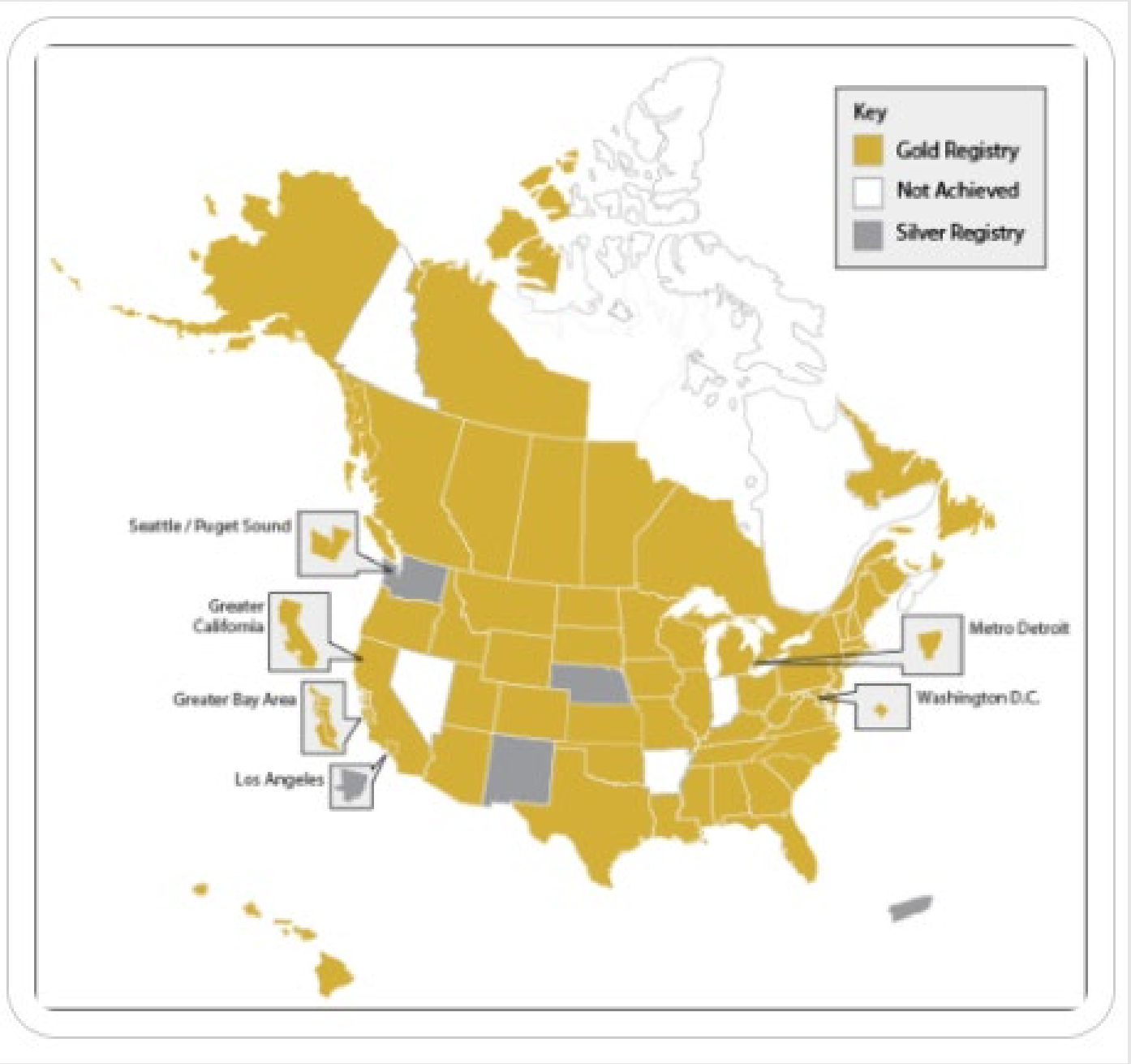
- https://www.naaccr.org/certification-criteria/
- Completeness – meets NAACCR Completeness Criteria
- Quality – meet 5 criteria
  - % DCO, % unknown county, % unknown age, % unknown race, 100% edit free, duplicates
- Timeliness – submission by December deadline
  - 23 months from close of diagnosis year
- Update—NAACCR Board Priority, changes coming

NAACCR Completeness

- NAACCR Completeness Estimate
  - Summary statistic
  - Oregon Incidence to Mortality Ratio compared to National Incidence (SEER) to Mortality (US) ratio
- Additional Measures to improve on method
  - Internal and external
    - Compare historic results; adjust for demographics
  - Completeness Metrics Tableau
    - Identify specific areas of completeness for the registry to focus on

2020 completeness estimates

- Standard NAACCR Completeness Method was not appropriate to evaluate case completeness for the 2020 data
  - Change in medical care access resulted in decrease of diagnosis
  - Change does NOT reflect decrease in burden of cancer
- Evaluated 2020 submission data & developed/applied adjustment
  - Goal 1: apply an adjustment that does not penalize registries for decreased # of cancer cases *diagnosed* due to changes in medical access
  - Goal 2: do not adjust away operational issues (due to covid or other factors) that resulted in decreased # of cancer cases *collected*
  - https://narrative.naaccr.org/article/winter-2023-research-data-use-update/
- Will evaluate 2021 submission data
  - Adjustment will be applied *if necessary*



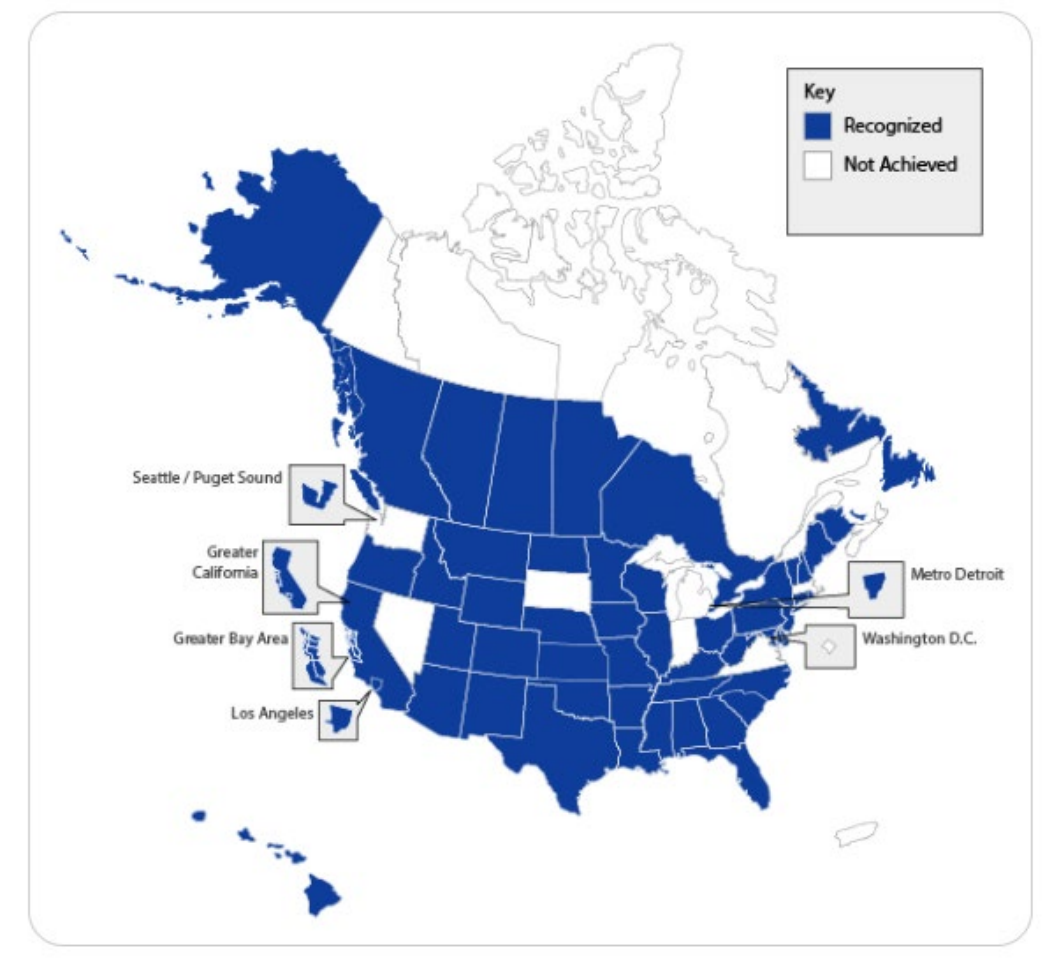
NAACCR GOLD CERTIFICATION

NAACCR SILVER CERTIFICATION

Additional evaluations

- Additional Recognitions:
  - Fit for Use: Survival/Prevalence
  - More coming……
- Data Assessments and Evaluation
  - Most recent 5 years of data for inclusion in CiNA
  - NAACCR Committee Work -- quality assessments & eval
    - Data Profiles https://www.naaccr.org/data-quality-assessments-and-evaluations/
    - Project specific evaluation
- Data Visualizations Tableau
  - Completeness metrics, CiNA eval, DQI

Fit for Use for Survival & Prevalence



What is CiNA?

- CiNA: Cancer in North America
- Data use of CFD submission file
- CiNA Data Products
  - On-line statistics, maps
  - Public Use datasets
  - Research Datasets
- How Oregon data are used in CiNA
  - Inclusion in all surveillance stats
  - Participation in research only if Oregon approves

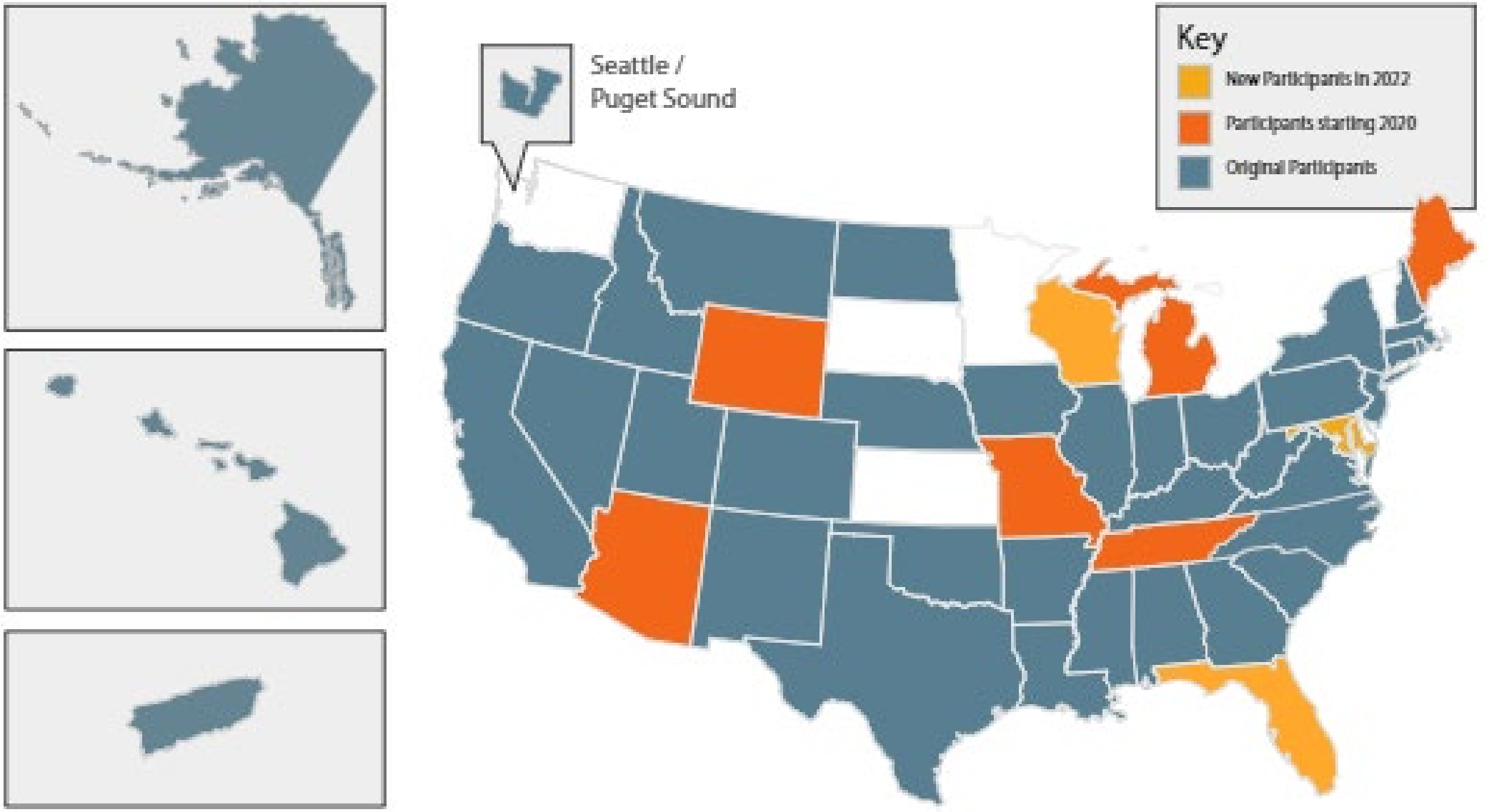
Cancer in North America data products (CiNA)

- Top 5 Cancers
  - https://www.naaccr.org/top-5-cancers/
- Interactive Statistics
  - NAACCR Cancer Maps (demo lung & bronchus cancer data)
    - https://www.cancer-rates.info/naaccr/
  - CiNA*Explorer (demo Oregon vs US by race/ethnicity, HPV-associated)
    - https://apps.naaccr.org/explorer/
- CiNA Research Datasets (released in SEER*Stat)
  - CiNA Public Use Dataset – annual permission to use Oregon data
    - https://www.naaccr.org/cina-public-use-data-set/
  - CiNA Research Files – project-specific to use Oregon data
    - https://www.naaccr.org/cina-data-products-overview/
  - Data requested through DaRT: https://apps.naaccr.org/dart/
    - Requires a free, MyNAACCR account to log-in

Virtual Pooled Registry Cancer Linkage System

The VPR-CLS is a secure online service that:

- efficiently connect researchers performing minimal risk linkage studies with multiple U.S. population-based cancer registries;
- perform linkages utilize a single cohort file, standard linkage software, and consistent matching algorithms;
- provide researchers with initial aggregate match count results across participating registries (Phase I); and
- streamline the process of applying for release of individual-level data on matched cases (Phase II).


Seattle /
Puget Sound
Key
New Participants in 2022
Participants starting 2020
Original Participants

Challenges to calculating cancer statistics

- Demographic
  - Race & ethnicity challenges (numerator & denominator)
  - Geocoding address
- 2020 cancer statistics

Race & Ethnicity Challenges

- Race is critical variable for assessing health inequities & identifying cancer control and prevention interventions
- Poor quality race data miss important conclusions and underestimate rates for minority populations
- Issues with census data: Bridged vs multiple race, incorrect apportionment of Hispanics by race, differential privacy 2020
- Issues with registry data: Increasing difficult to obtain, non-hospital sources often missing
  - Recodes and algorithmic supplementation
- Improvements to registry race data can be made by applying SEER coding rules & external linkages
- Best practices for both numerator and denominator and other resources being developed by NAACCR workgroups
- Some registries are not certified based on race
  - large-scale evaluation of extent of data availability is needed

Geocoding address at dx

- NAACCR Geocoder
- Batch (auto) vs interactive (manual)
- Poorly geocoded cases create bias
- Recent assessment by urban/rural at CT level
  - Removing poor quality cases resulted in incorrect comparison rates because rural cases are more likely to be poorly geocoded (also poor, older bias)
- Quality of incoming address data greatly influences geocoding burden

2020 Cancer Burden

- Caveats for rates
  - The COVID-19 pandemic disrupted access to medical care. This resulted in a drop in cancer diagnoses for the year 2020, particularly for cancers diagnosed before symptoms develop, such as in situ female breast cancer. This drop reflects changes in medical care for 2020 and should not be interpreted as a reduction in the underlying cancer burden.
- Remove from trends
  - New version of joinpoint

“Make Every Cancer Count”

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