

NAACCR  
CERTIFICATION  
AND THE CINA  
DATA  
SUBMISSION

FCDS 2023 VIRTUAL  
ANNUAL  
CONFERENCE:  
SESSION 3

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PROGRAM  
MANAGER OF DATA  
USE & RESEARCH,  
NAACCR

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# PRESENTATION OVERVIEW

- NAACCR Call for Data
  - Define processes that central registries are expected to perform
    - Death Clearance, Deduplication, Geocoding
  - Define process for evaluation
    - NAACCR Certification, CiNA Evaluation
      - Completeness, Quality, Timeliness
- How Florida data are used in CiNA

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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

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# NAACCR CALL FOR DATA (CFD) OVERVIEW

- Focus on NAACCR CFD <https://www.naaccr.org/call-for-data/>
  - Florida 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
    - Support NAACCR approved research (internal and external researchers)

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# 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

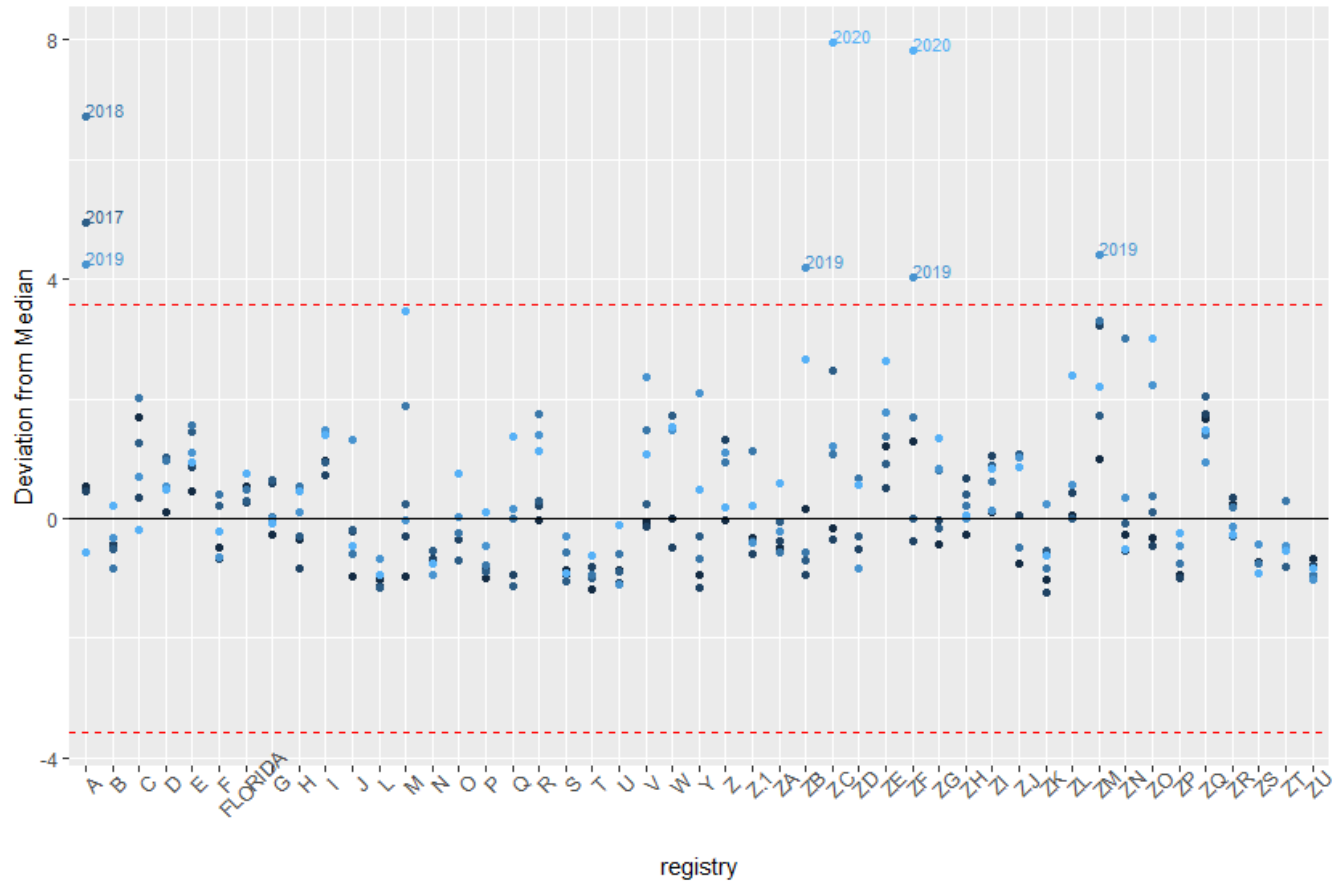
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# NAACCR CALL FOR DATA (CFD) PRE-PROCESSING

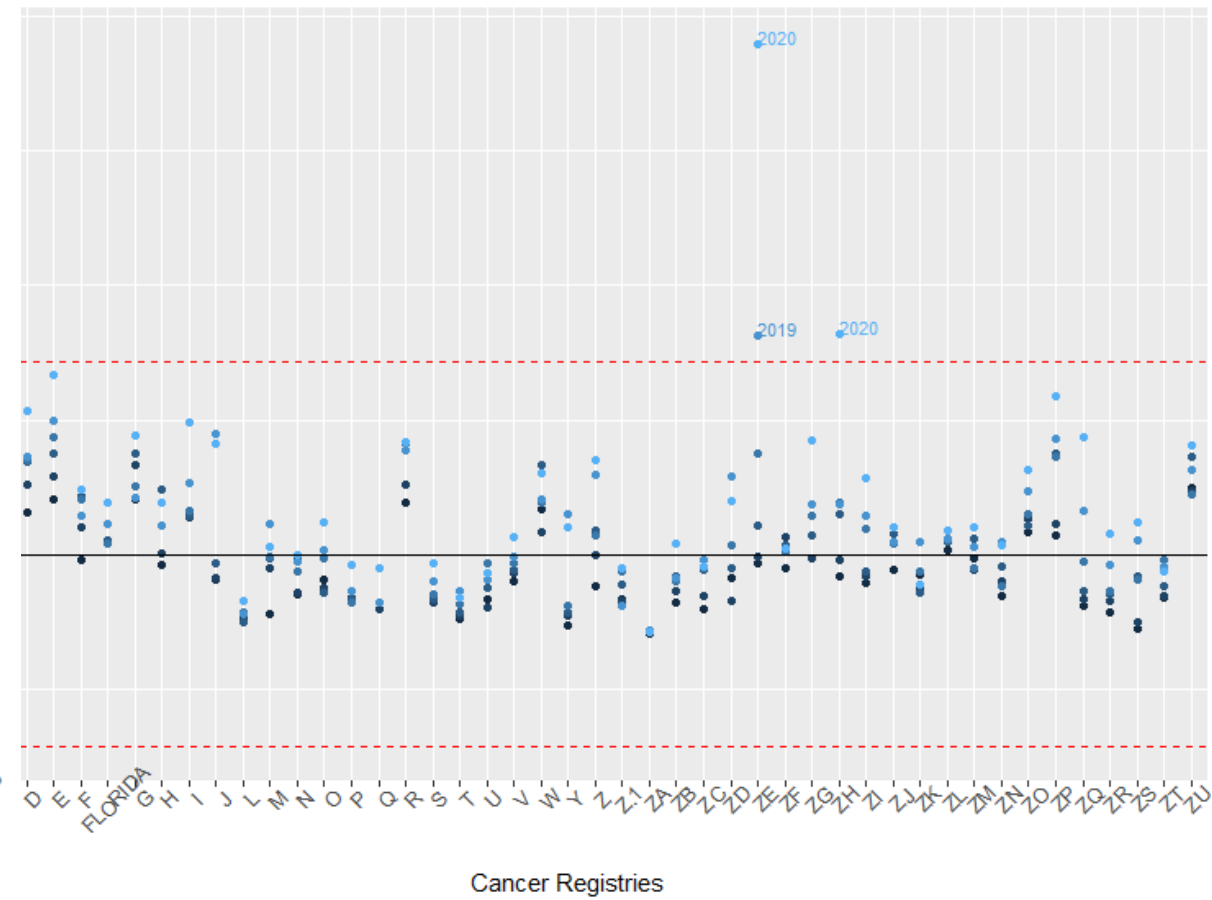
- Prior to creation of submission file
  - Case ascertainment
    - Death Clearance
    - Physician office reporting – unique effort by Florida
  - Deduplication
    - Updated protocol
    - Match\*Pro - Florida was directly involved in development
  - Geocoding
    - Patient address

# Proportion of Unknown Race by Leukemia & Myeloma cases

Proportion of unknown race for Leukemia & Myeloma cases



Proportion of unknown race for all cases except Leukemia & Myeloma



# NAACCR CALL FOR DATA (CFD) PRE-PROCESSING 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](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



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# NAACCR CALL FOR DATA (CFD) PRE-PROCESSING 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
      - 5 years deduplicated to meet the Criteria (Gold)
      - Next year 15 years will be deduplicated

# NAACCR CALL FOR DATA (CFD) PRE-PROCESSING 4

- Geocoding
  - Now on-going process; geocoder incorporated (API) into FCDS system
    - historically annual, 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 **NAACCR PREP**
  - 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 research

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# 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 may be coming



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# NAACCR COMPLETENESS

- NAACCR Completeness Estimate
  - Summary statistic
  - Florida Incidence to Mortality Ratio compared to National Incidence (SEER) to Mortality (US) ratio
- Additional Measures to improve on method
  - Internal and external
  - Completeness Metrics

# NAACCR COMPLETENESS CALCULATION

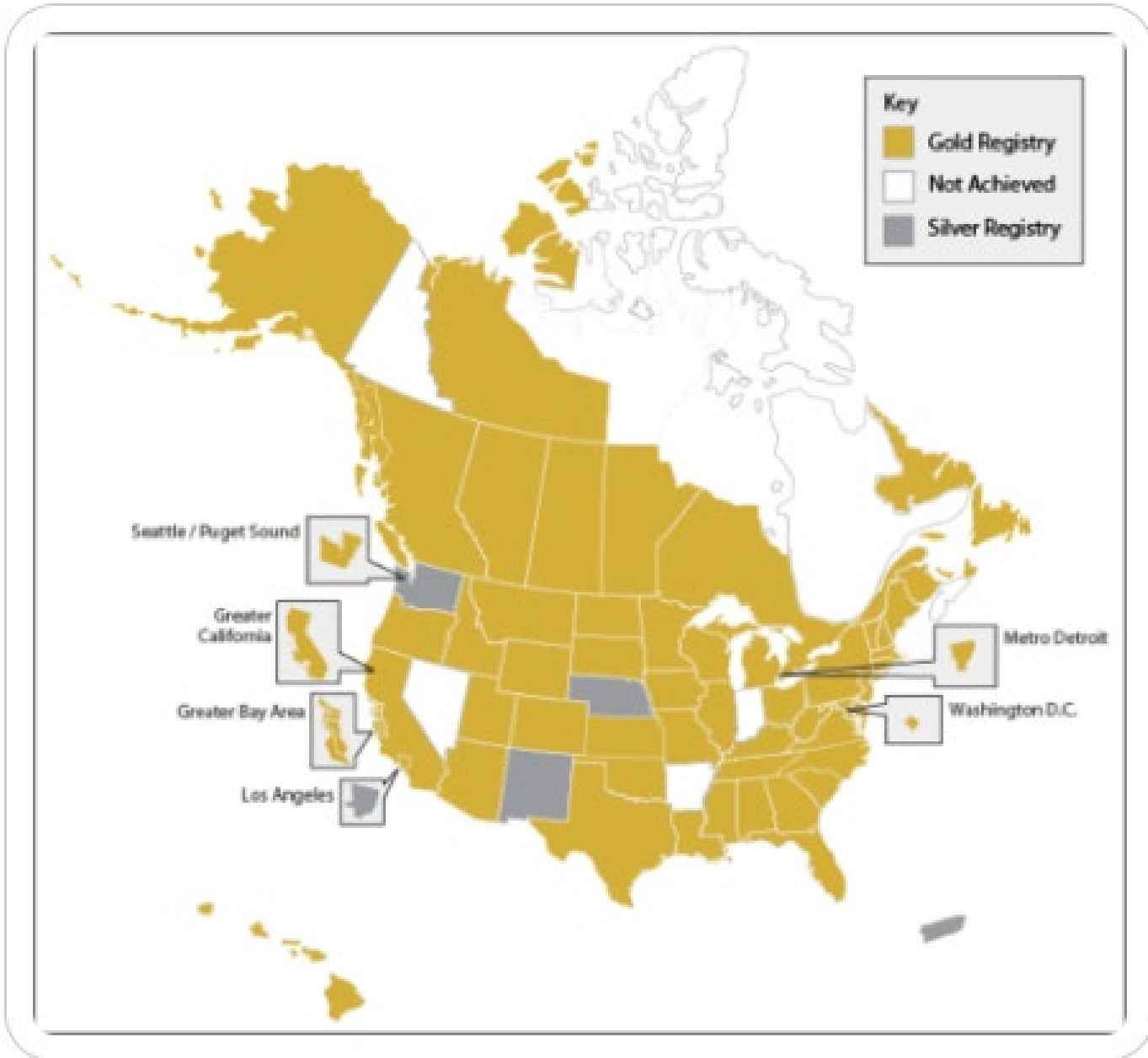
Worksheet for Completeness of Case Ascertainment, version 2.2.b													
Registry Incidence and Mortality Rates, by race/by sex (this example showing male sites)													
by race, by sex	Registry			SEER (11 Regs) and US Mortality			Unadjusted Results		Mortality Adjustment Terms			Adjusted for Mortality	
	Age-Adjusted Rates (2000 US)			Age-Adjusted Rates (2000 US)			Expected	Unadjusted	Registry		Adj Reg	Expected	Interim
	2020	2019-2020	Inc/Mort	2016-2020	2016-2020	Inc/Mort	Incidence	Percent	2016-2020	Adjust.	2019-2020	Incidence	Percent
	Incidence	Mortality	Ratio	Incidence	Mortality	Ratio	Rate	Complete	Mort Rate	Term	Mort Rate	Rate	Complete
Oral Cavity and Pharynx			0.00	12.25	4.25	2.88	-	0.0		1.0000	-	-	0.0
Esophagus			0.00	4.54	4.84	0.94	-	0.0		1.0000	-	-	0.0
Stomach			0.00	11.76	7.29	1.61	-	0.0		1.0000	-	-	0.0
Colon and Rectum			0.00	46.21	22.06	2.10	-	0.0		1.0000	-	-	0.0
Liver			0.00	15.73	11.00	1.43	-	0.0		1.0000	-	-	0.0
Pancreas			0.00	15.96	14.92	1.07	-	0.0		1.0000	-	-	0.0
Lung and Bronchus			0.00	62.08	52.38	1.19	-	0.0		1.0000	-	-	0.0
Melanomas of the Skin*			0.00	1.26	0.38	3.32	-	0.0		1.0000	-	-	0.0
Prostate*			0.00	167.47	36.99	4.53	-	0.0		1.0000	-	-	0.0
Bladder (including in situ)			0.00	19.65	5.21	3.77	-	0.0		1.0000	-	-	0.0
Kidney and Renal Pelvis			0.00	25.29	5.09	4.96	-	0.0		1.0000	-	-	0.0
Brain and Other Nervous System			0.00	4.57	3.22	1.42	-	0.0		1.0000	-	-	0.0
Hodgkin Lymphoma			0.00	2.88	0.31	9.34	-	0.0		1.0000	-	-	0.0
Non-Hodgkin Lymphoma			0.00	17.67	5.04	3.50	-	0.0		1.0000	-	-	0.0
Multiple Myeloma			0.00	15.98	7.23	2.21	-	0.0		1.0000	-	-	0.0
Leukemias			0.00	13.41	6.61	2.03	-	0.0		1.0000	-	-	0.0
Sum of Rates by race, by sex	-						-	0.0				-	0.0



# 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
    - Exclude 2020 in trend analysis
- 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.naacr.org/article/winter-2023-research-data-use-update/>
- Will evaluate 2021 submission data
  - Adjustment will be applied *if necessary*





# NAACCR CERTIFIED REGISTRIES FOR 2022 (BASED ON DIAGNOSIS YEAR 2020)

# 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





NAACCR REGISTRIES  
RECOGNIZED FIT FOR USE  
FOR  
SURVIVAL/PREVALENCE  
FOR 2022  
(BASED ON DIAGNOSIS  
YEARS 2008-2019)

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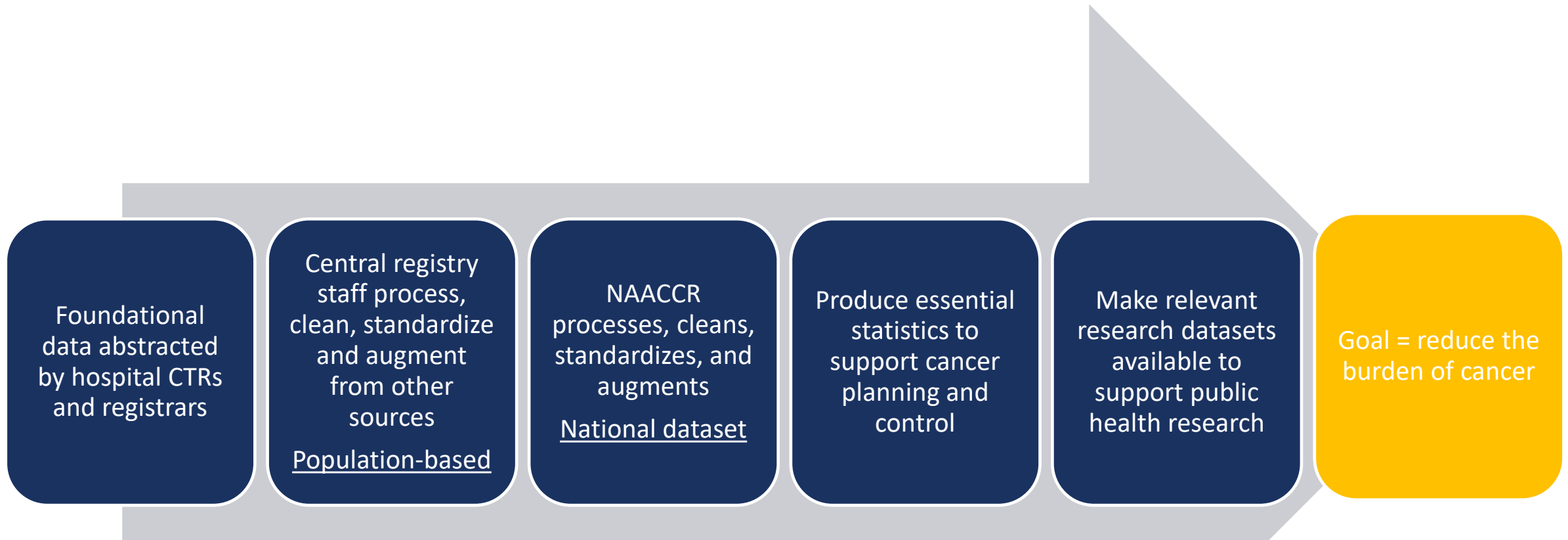
# DATA ASSESSMENT VISUALIZATIONS

- Demo Certification Criteria
  - DCO, Race
- Demo additional Completeness Metrics
  - % Non-Malignant Brain, % DCOs, % **Leukemia & Myeloma**, % Ill defined site, % Microscopically confirmed
- Demo CiNA Evaluation
  - Inclusion criteria, key data fields (unknown race)

# CANCER IN NORTH AMERICA DATA PRODUCTS (CINA)

- Top 5 Cancers
  - <https://www.naaccr.org/top-5-cancers/>
- Interactive Statistics
  - NAACCR Cancer Maps (demo oral cancer data)
    - <https://www.cancer-rates.info/naaccr/>
  - CiNA\*Explorer (demo Florida 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 Florida data
    - <https://www.naaccr.org/cina-public-use-data-set/>
  - CiNA Research Files – project-specific to use Florida 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

# “MAKE EVERY CANCER COUNT”



# QUESTIONS?

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