2018 NAACCR STANDARDS IMPLEMENTATION

VALUE OF CANCER REGISTRY DATA

Cancer registry data – essential for cancer control and oncology research

- Output of a complex, integrated, unique, continuously evolving data collection system
  - Data sets: SEER Research Database, USCS, NCDB PUF – among the most used medical research data sets
  - Quality and Usability differentiate cancer registry datasets from other data sources
- Data curation by cancer registrars – the core of this data engineering operation
  - Quality requires standards (manuals), training, tools
  - NCI SEER – part of its mission to improve quality assurance by providing manuals, trainings, tools and a data management system
- Data usability – from the perspective of researchers and public health professionals
  - Demand for additional clinically-relevant information
  - Need for integration with historical datasets and other oncology databases

Quality data curation and increased data usability are equally critical for the future of cancer registration!

ENSURE RELEVANCE OF CANCER REGISTRATION AS THE PILLAR OF CANCER SURVEILLANCE

Major changes in oncology practice: prognostic staging, predictive factors for precision systemic therapies, new radiation treatment options, focus on survivors experience, etc.

Quantitative and qualitative changes in informatics: access to new electronic data streams, exponential increase in the capability to conduct linkages

Changes in WHO Classification of Tumours

Steps to preserve and increase the usability of cancer registration data
- Adopt the latest (8th) new edition of AJCC Staging Manual
- Adopt and integrate the 4th edition of WHO Classification of Tumuors series
- Harmonize NAACCR Standards with the CAP Protocols
- Develop a staging system that covers all new cancer diagnosis (beyond AJCC, but harmonized with AJCC)
- Create the frame for expanding radiation therapy data collection

BALANCE BETWEEN "CONTINUOUS AND SYSTEMATIC COLLECTION" VS. INCREASED DATA USABILITY

Disruption of "continuous" data collection by unsynchronized changes to data standards may result in:

- Decreased timeliness of reporting
- Difficulties in compliance with state reporting requirements
- Decline of data quality indicators
- Inefficiencies in cancer registry operations

Goal of preserving/increasing usability needs to:

- be balanced against 'harms' to data quality
- reflect current budgets/resources

NCI'S EFFORTS TO SUPPORT STANDARDS UPDATES NOVEMBER 2016 – MARCH 2018

✓ **Developed the Extent of Disease system** to facilitate the capture of core staging data items and derive stage automatically
- EOD in SEER*RSA; Summary Stage 2018 Manual; SEER*API, Java and C# libraries

✓ **Worked to implement WHO Classification** of Tumours 4th editions
- Partnered with AJCC and CDC to clarify AJCC TNM staging eligibility requirements
- Provided leadership and technical support for the NAACCR ICD-O-3 workgroup

✓ Provided leadership, technical and financial **support for the NAACCR Site Specific Data Items** workgroup (prognostic factors, AJCC data items, grade data items)

✓ **Updating Solid Tumor** (aka MP/H) rules to reflect new WHO Classifications

✓ Developing **training presentations** (SSDI, EOD) and provided financial support to **SEER*Educate updates**

NCI SEER PRIORITIES:
THE 2018 NAACCR STANDARDS IMPLEMENTATION (AND BEYOND)

1. Complete the release of **informatics tools for vendors** (SEER*API, Java and C# libraries)

2. Update the **SEER*DMS system** and **SEER*Abs tool**

3. Update **manuals** from draft to fully compliant final versions (Summary Stage 2018, Solid Tumor, EOD general rules, Grade manual, SSDI manual, SEER Program manual)

4. Create/support **training opportunities**: SEER*Educate, presentations & workshops at annual meetings NCRA and NAACCR; workshops and trainings at state registrars assoc. events; update SEER Training website

5. Increase the support for **cancer registrars inquiry tools** (including CAnswer forum SSDI questions)

6. Work with SEER registries to consider temporary adjustments to **data quality measures** and future **submission specifications**

Make a high priority goal to work with registrars in the field and the NAACCR community toward developing and implementing the most effective change management policies!