Attachment 5

NATIONAL PROGRAM OF CANCER REGISTRIES
PROGRAM STANDARDS, 2017-2022

Performance Measures: A functional central cancer registry must be able to support and participate in the following activities:

- Report cancer incidence trends by geographic area and provide cancer data in support of cancer control programs.
- Collect and report incidence, burden, and stage data that can direct targeted interventions and be used to evaluate the success of cancer prevention and screening programs.
- Identify disparities by age, gender, race/ethnicity and geographic areas in cancer incidence, stage at diagnosis, and mortality.
- Create and maintain registry and state policies supportive of research uses of cancer registry data.

Purpose: The purpose of these standards is to:

- Ensure that cancer registries fulfill the overarching performance measures listed above.
- Establish priorities and activities that funded programs are expected to achieve.
- Provide objective measures of program progress.
- Improve program processes that ultimately affect outcomes.

The following are CDC's Program Standards for the National Program of Cancer Registries (NPCR). These standards are based on authority provided to the CDC under the Public Health Service Act (Title 42, Chapter 6A, Sub-Chapter II, Part M, § 280e) and subsequent amendments, and apply to all reportable cancers as defined in the Act and amendments. The CDC NPCR Program Standards may change during the project period of the cooperative agreement.

STRATEGY #1 Program Collaboration

Support collaboration across NBCCEDP, NCCCP, NPCR, and other chronic disease programs.

- The central cancer registry actively collaborates in the state's comprehensive cancer control planning efforts.

- The central cancer registry establishes a working relationship with other cancer control programs, including screening programs and tobacco control programs, to assess and implement cancer control activities.

- The central cancer registry establishes and regularly convenes an advisory committee to assist in building consensus, cooperation, and planning for the registry and to enhance chronic disease program coordination and collaboration. Representation should include

key organizations and individuals both within (such as representatives from all cancer prevention and control components and chronic disease program) and outside the program (such as hospital cancer registrars, the American Cancer Society, American College of Surgeons liaison, clinical-laboratory personnel, pathologists, and clinicians). Advisory committees may be structured to meet the needs of the state/territory such as the Comprehensive Cancer Control Program committee structure, an advocacy group, or a focus group.

STRATEGY #2 External Partnerships

Convene, support, and sustain partnerships and/or networks necessary to support implementation of cancer program priorities and activities.
- Establish and convene an Advisory Committee to assist in enhancing and utilizing the central cancer registry data for cancer prevention and control and other chronic diseases, also for coordinating and collaborating with other cancer programs.

- Utilize the Advisory Committee to develop and refine quality improvement initiatives.

- Establish and promote greater awareness and utilization of the cancer registry data.

STRATEGY #3 Cancer Data and Surveillance

Legislative Authority
- The state/territory has a law authorizing a population-based central cancer registry.

- The state/territory has legislation or regulations in support of Public Health Service Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e, authorizing the National Program of Cancer Registries.

Administration/Operations
- Establish or retain staff sufficient in number and expertise to manage, implement, and evaluate the central cancer registry, as well as utilize and disseminate the data. Core staff must fill the roles of Program Director/Project Director/Principal Investigator, Quality Assurance/Quality Control Manager, and Education and Training Coordinator positions must be filled by qualified, experienced Certified Tumor Registrars (CTRs).

- The central cancer registry maintains an operations manual that describes registry operations, policies and procedures. At a minimum the manual contains the following:
    1. Most current reporting laws/regulations
    2. List of reportable diagnoses
    3. List of required data items
    4. Procedures for data processing operations including:
        a) Procedures for monitoring timeliness of reporting
        b) Procedures for receipt of data
        c) Procedures for database management including a description of the

Registry Operating System (software). This may be accomplished by citing a software vendor website and available documentation.
- d) Procedures for conducting death certificate clearance
- e) Procedures for implementing and maintaining the quality assurance/control program
    - i. Procedures for conducting follow-back to reporting facilities on quality issues. These procedures include rules for identifying when action or further investigation is needed
    - ii. Procedures for conducting record consolidation
    - iii. Procedures for maintaining detailed documentation of all quality assurance operations.
    - iv. Procedures for education and training
- 5. Procedures for conducting data exchange including a list of states with which case-sharing agreements are in place
- 6. Procedures for conducting data linkages
- 7. Procedures insuring confidentiality and data security including disaster planning
- 8. Procedures for data release including access to and disclosure of information
- 9. Procedures for maintaining and updating the operational manual
- 10. The central cancer registry has management reports that include processes and activities to monitor the registry operations and database.
- 11. The central cancer registry has an abstracting and coding manual that is made available to and used by reporting sources that abstract and report cancer cases.

Data Collection, Content, and Format
- Central cancer registries must collect and submit data for all reportable cancers and benign neoplasms, including at a minimum, primary site, histology, behavior, date of diagnosis, race/ethnicity, age at diagnosis, gender, stage at diagnosis, first course of treatment according to CDC specifications, and other information required by CDC.

- For all CDC required reportable cases, the central cancer registry collects or derives all required data items using standard codes as prescribed by CDC.

- Regardless of residency, the central cancer registry collects data on patients diagnosed and/or receiving first course of treatment in the registry's state/territory.

- The central cancer registry uses a standardized, CDC-recommended data exchange format to transmit data to other central cancer registries and CDC.

Data Quality Assurance and Education
- The central cancer registry has an overall program of quality assurance that is defined in the registry operations manual. The quality assurance program consists of, but is not limited to:
    - o A designated certified tumor registrar (CTR) responsible for the quality assurance program.
    - o Quality assurance activities should be conducted by qualified experienced CTR(s) or CTR-eligible staff.

- o Data consolidation procedures are performed according to the central cancer registry protocol and nationally accepted abstracting and coding standards as available.
- o At least once every 5 years, a combination of case-finding and re-abstracting audits from a sampling of source documents are conducted for each hospital-based reporting facility, and may include external audits by CDC or SEER.
- o Audits of a routine sample of consolidated cases at the central cancer registry.
- o Feedback is provided to reporting sources on data quality and completeness.

- The central cancer registry has an overall education program that is defined in the registry operations manual. The education program consists of, but is not limited to:
  - o Training for central cancer registry staff and reporting sources to assure high quality data.
  - o A designated education/training coordinator who is a qualified, experienced CTR.
  - o Where feasible, the education/training coordinator may be regionally-based, such that CDC-NPCR applicants collaborate to identify one applicant to provide the education/training coordinator for activities to be carried out in the full region.

Data Submission
- The central cancer registry annually submits data files to the NPCR-Cancer Surveillance System (CSS) that meet the reporting requirements outlined in the NPCR-CSS Submission Specifications document and meet criteria for publication in *United States Cancer Statistics*.

- In appropriate data submission years, where the central cancer registry data file meets specified data completeness and quality standards, the central cancer data are included in the *Cancer in Five Continents* publication.

- Participation in all CDC-created and hosted analytic datasets and web-based data query systems according to the annual NPCR CSS Data Release Policy.

Data Use and Data Monitoring

- Within 12 months of the end of the diagnosis year with data that are 90% complete, the central cancer registry produces preliminary pre-calculated data tables in an electronic data file or report of incidence rates, counts or proportions for the diagnosis year by Surveillance Epidemiology and End Results (SEER) site groups to monitor the top cancer sites within the state/territory.

- Within 24 months of the end of the diagnosis year with data that are 95% complete, the central cancer registry, in collaboration with local cancer control programs, produces electronic reports to include the following:
    1. Reports on age-adjusted incidence rates, stage at diagnosis, and age-adjusted mortality rates for the diagnosis year using SEER site groups and, where applicable, stratifying by sex, race, ethnicity, and geographic area.
    2. Biennial reports providing data on stage and incidence by geographic area with an emphasis on screening-amenable cancers and cancers associated with modifiable risk factors (e.g., tobacco, obesity, HPV).

- The central cancer registry ensures annual use of cancer registry data for public health and surveillance research purposes in at least five of the following ways:
    1. Comprehensive Cancer Control.
    2. Detailed incidence/mortality by stage and geographic area.
    3. Collaboration with cancer screening programs for breast, colorectal, or cervical cancer.
    4. Health event investigation(s).
    5. Needs assessment/program planning (e.g., Community Cancer Profiles).
    6. Program evaluation.
    7. Epidemiologic studies.
- The central cancer registry submits a success story to CDC at least annually detailing how registry data have been used to impact public health.

Electronic Data Exchange
- The central cancer registry is required to adopt and utilize standardized, CDC-recommended data transmission formats for the electronic exchange of cancer data (see CDC NPCR Electronic Reporting and Data Exchange Guidance).   Registries also promote the use of these formats by reporting sources that transmit data electronically to the registry. CDC-recommended data exchange formats include:
    1. Hospital reporting: The NAACCR record layout version specified in year-appropriate *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary.*
    2. Anatomic Pathology Laboratory Reports: *NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting* (Version 2.2 or higher).
    3. Non-hospital sources using electronic medical records: Integrating the Healthcare Enterprise (IHE) Provider Reporting to Public Health-Cancer Registry (PRPH-Ca) Profile. For hospitals reporting to the central cancer registry, annually increase the percent reporting electronically to meet the standard of having all of these facilities reporting electronically by the end of the five year project period.

- For non-hospital facilities reporting to the central cancer registry, annually increase the percent reporting electronically to meet the standard of having at least 80% of these facilities reporting electronically by the end of the five year project period.

- The central cancer registry uses a secure Internet-based, FTP, https, or encrypted email mechanism to receive electronic data from reporting sources.

- The central cancer registry has a plan to implement a mechanism for receiving and processing data from electronic medical records (EMRs) over the 5 year project period; and will coordinate with CDC to develop plans for more rapid implementation if cancer reporting is included in Stage II of Meaningful Use.

- The central cancer registry should submit the NPCR Hospital, Path Lab, and Physician Reporting Progress Report form with the Annual Report.

Strategy #4 Community Level Interventions and Patient Support

- Disseminate cancer surveillance data with NCCCP and NBCCEDP programs, and other organizations/agencies as identified by the registry's Advisory Committee, to implement community level and patient support interventions

STRATEGY #5 Health Systems Change

Linkages
- The central cancer registry links with state death files at least every year and incorporates results on vital status and cause of death into the registry database.

- The central cancer registry should link with the National Death Index annually, and incorporates results on vital status and cause of death into the registry database.
- The central cancer registry links with the state breast and cervical cancer early detection program at least once a year to identify potentially missed cases, reconcile differences between the two systems, and update appropriate data field to capture post-linkage information.

- The central cancer registry links with IHS at least every five years. Central cancer registries with IHS Contract Health Service Delivery Area counties link their records with patient registration records from IHS annually.

- The central cancer registry utilizes linkages to address gaps identified in data quality and completeness or to improve the utility of the data. Potential sources of information include the following:
    1. Statewide electronic health files for case-finding and completeness of required data items
    2. Claims data for case-finding and completeness of required data items

3. Census data (or similar) for socio-demographic variables
4. Birth records for demographic information
5. Department of Motor Vehicle records for demographic information
6. Voter registration files for demographic information

STRATEGY #6 Program Monitoring and Evaluation

Data Completeness/Timeliness/Quality
- Data being evaluated for the National Data Quality Standard (formerly known as the 24-Month Standard), must meet the following five data quality criteria:
    1. Data are 95% complete based on observed-to-expected cases as computed by CDC.
    2. There are 3% or fewer death-certificate-only cases.
    3. There is a 1 per 1,000 or fewer unresolved duplicate rate.
    4. The maximum percent missing for critical data elements are:
        a. 2% age
        b. 2% sex
        c. 3% race
        d. 2% county
    5. 99% pass a CDC-prescribed set of standard edits

- Data being evaluated for the Advanced National Data Quality Standard (formerly known as the 12-Month Standard), must meet the following data quality criteria:
    1. Data are 90% complete based on observed-to-expected cases as computed by CDC.
    2. There is a 2 per 1,000 or fewer unresolved duplicate rate
    3. The maximum percent missing for critical data elements are:
        a. 3% age
        b. 3% sex
        c. 5% race
        d. 3% county
    4. 97% pass a CDC-prescribed set of standard edits.

- Annually increase the reporting by urologists, dermatologists, and gastroenterologists that report to the central cancer registry, as required by state law, in order to meet the standard of having most of these physicians reporting by the end of the 5-year project period (see CDC NPCR Physician Reporting Guidance).

- Annually increase the reporting by medical oncologists, radiation oncologists, and hematologists that report to the central cancer registry, as required by state law, in order to meet the standard of having most of these physicians reporting by the end of the 5-year project period (see CDC NPCR Physician Reporting Guidance).

- The cancer registry participates in the national data exchange to the extent possible, when allowed by state law, and exchanges data with all bordering central cancer

registries and other central registries most likely to yield missed cases and implements data sharing agreements as needed. Data exchange must meet the following minimum criteria:

1. Occurs within 12 months of the close of the diagnosis year.
2. Occurs at least twice a year.
3. Includes all cases not previously exchanged.
4. Includes all CDC-required data items.
5. 99% of data pass a CDC-prescribed set of standard edits.

- The cancer registry is required to complete and submit the NPCR Program Evaluation Instrument (PEI) bi-annually.