

NEW NPCR PROGRAM STANDARDS:

The Process & the Product

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Purpose of NPCR Standards

- Guide priorities and activities of funded programs over the next five years
- Provide objective measures of program progress
- Improve program processes that ultimately affect outcomes



History ⁽¹⁾

- **Standards developed for 1st Program Announcement**
- **Wide variation in performance and activities between programs**
- **Purposes of standards**
 - **Build infrastructure**
 - **Bring all programs up to minimum standards**



History ⁽²⁾

- 1st standards were process oriented
- Standards in place for 5 years
- Developed an Annual Program Evaluation Instrument (APEI)
- Some questions based on Standards



History ⁽³⁾

- NPCR Program Objectives developed around standards
- Set with the goal of obtaining a high percent of compliance in the next 5 years
 - Example: By the year 2005, 95% of funded States will collect or derive, for reportable cancer cases, uniform data elements in a standardized format as currently prescribed by NPCR pursuant to PL 102-515.
- **APEI used to measure progress**



History ⁽⁴⁾

- 2nd Program Announcement
- Standards reviewed and revised
- Standards moved from process to outcome orientation
 - Example:
 - 1st: All cases must be reported to the CCR within 6 months of diagnosis
 - 2nd: Within 24 months of the close of the diagnosis year, 95% of expected, cases are available to be counted at the CCR
- APEI revised



2005

States that have met **ALL** Current NPCR standards

- FLORIDA
- IDAHO



- NEW YORK
- RHODE ISLAND

Many states have met **MOST** of the standards

Current Standards Compliance

Standard	% meeting
1. Legislative Authority	100%
2. Data Content & Format	
a. Required data elements	76%
b. Proscribed codes	100%
c. Recommended data exchange record layout	100%
3. Data Completeness and Timeliness	
a. 90% at 12 months	17%
b. 95% at 24 months	65%
c. 3% or fewer DCOs in 24 months	81%



Current Standards Compliance

Standard	% meeting
3. Data Completeness and Timeliness	
d. 1 or fewer duplicate cases per 1,000 at 24 months	98%
e. Performs death clearance and follow-back	94%
4. Data Quality	
a. 97% pass data edits at 12 months	83%
b. 99% pass edits at 24 months	100%
5. Annual Report	13%
6. Data Use	76%
7. Data Monitoring:	100%



The Current Process ⁽¹⁾

- **Process of reviewing and revising standards for next Program Announcement**
 - ORTA Team took lead
 - Standards development retreat
 - Involved participants from other teams
 - Used data from APEI and 2005 data submission
 - Establish percent compliance with current standards



The Current Process (2)

- Team discussed future directions
- All programs have not met all current standards
- Kept most of the previous standards
- Reworded some for clarity
- Most programs are close to meeting minimum standards
- Need to expand expectations
- Added new standards



The Current Process ⁽³⁾

- Standards sent to editorial services
- Presented Standards to Branch
- Mailed first draft to all programs and invited comments
- Used comments to revise standards
- Distributed second draft to programs and Branch
- Received comments and questions
- Made minimal changes



The Current Process (4)

- **Developed Frequently Asked Questions**
- **Presented Standards at Program Directors meeting**
- **Included FAQ's in Program Director's notebook**
- **Draft format until included in next Program Announcement**



New: **Administration** ⁽¹⁾

- **New Standard**

A. The CCR maintains an operational manual that describes registry operations, procedures and policies. At a minimum the manual contains the following:

- 1. Reporting laws and regulations**
- 2. List of reportable diagnoses**
- 3. List of required data items**
- 4. Procedures for monitoring timeliness of reporting**



New: **Administration** (2)

A. (continued)

5. Procedures for receipt of data
6. Procedures for data management including a description of registry operating system (software)
7. Procedures for data processing operations
8. Procedures for conducting death certificate clearance



New: Administration (3)

A. (continued)

9. Procedures for implementing and maintaining quality assurance/control program

- a. Procedures for conducting follow-back to reporting facilities on quality issues. These procedures include rules for identifying when action or further investigation is needed.
- b. Procedures for conducting record consolidation.
- c. Procedures for maintaining detailed documentation of all quality assurance operations.



New: **Administration** (4)

A. (continued)

10. Procedures for conducting data exchange including a list of case-sharing agreements
11. Procedures insuring confidentiality and data security
12. Procedures for data release including access to and disclosure of information
13. Procedures for maintaining and updating the operational manual



New: Administration (5)

- **New Standard**

B. The CCR has management reports that monitor the registry operations and database.



New: **Electronic Data Exchange** ⁽¹⁾

- **New Standard**
 - A. The CCR uses and requires a standardized, NPCR-recommended data exchange record layout for the electronic exchange of cancer data. NPCR-recommended data exchange layouts include:



New: Electronic Data Exchange ⁽²⁾

A. (continued)

1. For abstracted data: The NAACCR record layout version specified in *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary*.
2. For pathology reporting: *NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting*



New: Electronic Data Exchange ⁽⁴⁾

- B. At a minimum, 95% of *reports* from **hospitals** are submitted to the CCR in an electronic format (where medical records are owned by the hospital).
- Includes all non-federal, military, VA, Indian Health Services and tribally owned hospitals.



New: Electronic Data Exchange ⁽⁵⁾

C. At a minimum, 85% of *reports* from **non-hospital reporting sources** are submitted to the CCR in an electronic format (e.g. radiation therapy centers, ambulatory surgery centers, and in-state and out-of-state pathology laboratories where medical records are owned by the reporting source)



New: Electronic Data Exchange ⁽⁷⁾

- D. At a minimum, 75% of *reports* from **physician offices** identified as required to submit cancer cases to the CCR do so in an electronic format (where medical records are owned by the physician). This includes responses from physicians to CCR inquiries.
- E. The CCR primarily uses a secure Internet-based, or encrypted email mechanism to receive data from all reporting sources



NPCR Tools

- **Free data collection software**
 - **Abstract Plus**
 - Useful for:
 - Small hospitals without a cancer registry
 - Other non-hospital reporters
 - When facility does not have internet access
 - **Web Plus**
 - Useful for:
 - Facilities without a cancer registry
 - When facility has web access
- **National electronic pathology reporting support**



Data Completeness- Timeliness-Quality ⁽¹⁾

- **New Standard**
 - A. **Within 24 months of the close of the diagnosis year, at least 75% of physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients submit all reportable cases to the central cancer registry, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities (based on PL 102-515)..**



Data Completeness- Timeliness-Quality ⁽¹⁾

- **New Standard**

D. Within 12 months of the close of the diagnosis year, the CCR exchanges data with other CCRs where a data-exchange agreement is in place.

- 1. Regardless of residency, the CCR collects data on all patients diagnosed and/or receiving first course of treatment in the registry's state/territory.**
- 2. The recommended frequency for data exchange is, at a minimum, two times a year.**



Data Completeness- Timeliness-Quality ⁽²⁾

D. (continued)

3. Exchanged data must meet the following minimum criteria:
 - a. Exchange agreements are in place with all bordering states.
 - b. Exchanged data include a dataset that consists of NPCR core data items.
 - c. 97% of data pass an NPCR-prescribed set of standard edits.
 - d. The dataset is transmitted via secure encrypted Internet-based system.
 - e. A standardized, NPCR-recommended data exchange format is used to transmit data



New: Data Quality Assurance (1)

- **New Standard:**

A. The CCR has an overall program of quality assurance that is defined in the registry operations policy and procedure manual. The quality assurance program consists of, but is not limited to:

- 1. A designated CTR is responsible for the quality assurance program.**
- 2. Qualified, experienced CTR(s) conduct quality assurance activities.**



New: Data Quality Assurance (2)

A. (continued)

3. At least once every five years, case-finding and/or re-abstracting audits from a sampling of source documents are conducted at each hospital-based reporting facility.
4. Data consolidation procedures are performed according to an accepted protocol.
5. Procedures are performed for follow-back to reporting facilities on quality issues.



New: Data Quality Assurance ⁽³⁾

- **New Standard (continued)**

B. The CCR has a designated education/training coordinator who is a CTR to provide training to the CCR staff and reporting sources to assure high quality data.



Data Use ⁽¹⁾

- **NEW Standard: reworded**
 - A. Within 12 months of the end of the diagnosis year with data that is 90% complete, the CCR produces preliminary pre-calculated data in tables in an electronic data file or report of incidence rates, counts, or proportions for the diagnosis year for SEER site groups.**



Data Use ⁽²⁾

- **New Standard**

C. The CCR, state health department, or its designee uses registry data for planning and evaluation of cancer control objectives in at least three of the following ways annually:

- 1. Comprehensive cancer control**
- 2. Detailed incidence/mortality estimates**



Data Use ⁽³⁾

C. (cont.)

3. Linkage with a statewide cancer screening program to improve follow-up of screened patients
4. Health event investigation (s)
5. Needs assessment/program planning
6. Program evaluation
7. Epidemiologic studies



New: Collaborative Relationships (1)

- **New Standard**
 - A. **The CCR actively collaborates in the state's comprehensive cancer control planning efforts.**
 - B. **The CCR establishes a working relationship with all components of the cancer prevention and control program to ensure the use of registry data to assess and implement cancer control activities.**



New: Collaborative Relationships (2)

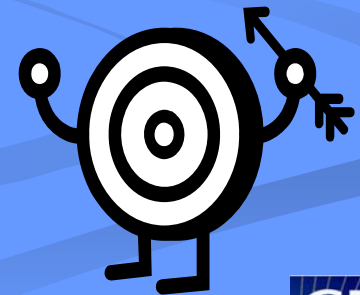
- New Standard (continued)
- C. The CCR establishes and regularly convenes an **advisory committee** to assist in building consensus, cooperation, and planning for the registry. Representation should include key organizations and individuals both within (such as representatives from all cancer prevention and control components) and outside the program (such as hospital cancer registrars, the American Cancer Society, clinical-laboratory personnel, pathologists, and clinicians).





QUESTIONS

Comments/ suggestions



THANK YOU

