09-CD-01

Committee: Chronic

Title: Public Health Reporting and National Notification for Cancer and Central Nervous System Tumor Incidence and Mortality

I. Statement of the Problem

CSTE position statement 07-EC-02 recognized the need to develop an official list of nationally notifiable conditions and a standardized reporting definition for each condition on the official list. The position statement also specified that each definition had to comply with American Health Information Community recommended standards to support "automated case reporting from electronic health records or other clinical care information systems." In July 2008, CSTE identified sixty-eight conditions warranting inclusion on the official list, each of which now requires a standardized reporting definition.

II. Background and Justification

Background

Incidence and mortality of cancers and benign and borderline central nervous system tumors should be placed under nationwide surveillance as part of a national public health surveillance system, and the system, at a minimum, should monitor and report on all:

- invasive cancers at all sites with the exception of basal cell and squamous cell carcinoma of the skin;
- *in situ* cancers at all sites with exception of carcinoma *in situ* of the cervix uteri, or any intraepithelial neoplasia (CIN, PIN, etc.); and
- benign and borderline central nervous system tumors.

Monitoring the burden of cancers and benign and borderline central nervous system tumors is needed to: measure the effectiveness of early detection programs and interventions; to focus cancer control activities and resources; and to aid public health surveillance and research efforts in reducing the morbidity and mortality due to cancer and benign and borderline central nervous system tumors. Resources are available for surveillance of cancer and central nervous system tumor incidence and mortality, and all states have a cancer registry that is statewide and population-based. Uniform data standards and data collection procedures are published and updated annually by the North American Association of Central Cancer Registries (NAACCR). The standards are developed collaboratively by participating central cancer registries and major national organizations, including the Centers for Disease Control and Prevention (CDC), the National Cancer Institute (NCI), the American Cancer Society (ACS), the American College of Surgeons (ACoS), the American Joint Committee on Cancer (AJCC), and the National Cancer Registrars Association (NCRA). All states have adopted supporting statewide legislation and regulations for case ascertainment, implemented procedures for electronic data collection and

transmission, and use standardized edits and other quality control procedures. Both commercial and public use software is available to facilitate uniform reporting of incident cases.

Justification

Cancer and central nervous system tumor incidence and mortality meet the following criteria for a national and **standard** notifiable condition, as specified in CSTE position statement 08-EC-02:

- All states and territorial jurisdictions—or jurisdictions comprising a majority of the US population—have laws and/or regulations requiring **standard** reporting of cancer incidence and mortality to public health authorities
- CDC-NPCR requests **standard** notification of cancer incidence to federal authorities for 48 CDC-NPCR funded central cancer registries: 45 states, the District of Columbia, one territory, and the Pacific Island jurisdictions. The NCI's Surveillance, Epidemiology, and End Results (SEER) Program requests **standard** notification of cancer incidence from the remaining 5 states.
- CDC-National Center for Health Statistics (NCHS) requests **standard** notification of mortality from state vital statistics systems to federal authorities for the 50 states, the District of Columbia, New York City, and five territories.
- CDC has condition-specific policies and practices concerning the agency's response to, and use of, notifications.

III. Statement of the desired action(s) to be taken

CSTE requests that CDC-NPCR, NCI-SEER, CDC-NCHS and other national surveillance organizations collaboratively continue to maintain these standardized reporting definitions for cancer and central nervous system tumor incidence and mortality to facilitate timely, complete, and standardized local and national reporting of these conditions.

IV. Goals of Surveillance

Surveillance provides information on the temporal, geographic, and demographic occurrence of, and mortality from, cancer to facilitate its prevention and control. Data collected by central cancer registries help public health professionals understand and address the nation's cancer burden. Vital information about cancer cases and cancer deaths is necessary for health agencies to report on cancer trends, assess the impact of cancer prevention and control efforts, participate in research, and respond to reports of suspected increases in cancer occurrence.

V. Methods for Surveillance

Surveillance for cancer incidence and mortality should use the sources of data and the extent of coverage listed in Table V.

Table V. Recommended sources of data and extent of coverage for ascertaining cancer and benign and borderline central nervous system tumors incidence and mortality.

Source of data for cancer incidence and mortality	Coverage
	Population-wide
Clinical reporting	X
Laboratory reporting (anatomical pathology and cytology laboratory reporting)	X
Reporting by other health care entities (e.g. ambulatory surgical centers, radiation therapy centers, and other facilities providing screening, diagnostic, and treatment services to patients with respect to cancer)	X
Death certificates	X
Hospital inpatient and outpatient records	X
Cancer Registries	X

For cancer incidence data, a complete set of uniform core data items is collected from medical and laboratory records (and death certificates for cancer discovered at the time of autopsy) at the local level on all newly diagnosed *in situ* and invasive cancer cases (see exceptions in surveillance case definition, below), and benign and borderline central nervous system tumors, and transmitted to the appropriate central cancer registry, or to the state health department or its designee. Incidence data are compiled by the central cancer registry, or state health department or its designee, and then transmitted to either the NCI or CDC.

Information on deaths due to cancer is reported on death certificates to state health departments by clinicians, funeral directors, and other authorized persons. State vital statistics systems provide data on cancer mortality to the CDC-NCHS, which is available for national public health surveillance. The source for mortality data should be information from death certificates, preferably electronic, that is provided by state vital statistics systems to the CDC-NCHS. Also, state vital statistics systems exchange data with central cancer registries to enable registries to obtain more complete cancer mortality information for patient follow-up.

Data to be collected

For each form of cancer (as defined in Section VI, A below), data collection should include the following:

- Demographic information for each cancer case
- Administrative information, including the date of diagnosis and the reporting source
- Tumor characteristics including the cancer site and stage of disease
- Treatment type(s)

The data items, coding schemes, definitions, record layouts, and reporting procedures are to follow the guidance provided in the current issue of the North American Association of Central Cancer Registries' (NAACCR) *Data Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary,* or current version available at www.naaccr.org. The NAACCR

provides standards for data items collected on cancer cases as established by the national standards-setting organizations (e.g. CDC-NPCR, NCI-SEER, ACoS Commission on Cancer). These standards are annually updated and provide consensus across all central cancer registries for meaningful comparisons and compilation for national surveillance.

Several additional publications should be consulted for further information on data to be collected. States funded by the CDC-National Program of Cancer Registries should consult the *National Program of Cancer Registries Program Manual, Version 1.0* (http://www.cdc.gov/cancer/npcr/npcrpdfs/program_manual.pdf), which serves as a single reference that defines expectations and provides guidance on specific activities for the NPCR Programs. States funded by the NCI-SEER program should consult the *SEER Program Coding and Staging Manual,* which contains procedures for identifying cancer cases and abstracting and coding data obtained from clinical and pathological records on cases to be accessioned by SEER cancer registries.

In addition, the Commission on Cancer (CoC) of the ACoS publishes the *Facility Oncology Registry Data Standards,* or FORDS, Manual (FORDS 2007 http://www.facs.org/cancer/coc/fords/fordsrevised0605.pdf), which contains procedures for identifying cancer cases to be accessioned by hospital cancer (oncology) registries and for coding data obtained from clinical and pathological records on accessioned cases.

VI. Criteria for Reporting

Reporting refers to the process of health care providers or institutions (e.g., clinicians, laboratories, hospitals) submitting basic information to governmental public health agencies about cases of illness that meet certain reporting requirements or criteria. The purpose of this section is to provide those criteria that should be used by humans and machines to determine whether a specific illness should be reported.

A. Narrative description of criteria to determine whether a case should be reported to public health authorities:

Reportable cancer cases include:

- incident invasive cancers at all sites with the exception of basal cell and squamous cell carcinoma of the skin;
- incident *in situ* cancers at all sites with the exception of carcinoma *in situ* of the cervix uteri, or any intraepithelial neoplasia, (CIN, PIN, etc.); and
- incident benign and borderline central nervous system tumors

A diagnosis of *in situ* or invasive cancer by a recognized medical practitioner that includes the use of specific terms synonymous with cancer is sufficient. These terms include but are not limited to: "cancer," "malignant," "carcinoma," "sarcoma," "leukemia," and "lymphoma." In addition, a list of ambiguous terminology that is considered to indicate a reportable cancer includes: “appears”, “comparable with”, “presumed”, “probable”, “suspect(ed)”, and others (see NAACCR *Volume II, Data Standards and Data Dictionary* for complete list).

Other recommended reporting procedures

- Reporting should be on-going and routine, with the frequency of reporting following the guidance of the state health department or its designee.

B. Table of criteria to determine whether a case should be reported to public health authorities

Table VI-B. Table of criteria to determine whether a case should be reported to public health authorities. Requirements for reporting are established under State and Territorial laws and/or regulations and may differ from jurisdiction to jurisdiction. These criteria are suggested as a standard approach to identifying cases of this condition for purposes of reporting, but reporting should follow State and Territorial law/regulation if any conflicts occur between these criteria and those laws/regulations.

Criterion	**Reporting**			
	benign and borderline central nervous system tumors	*in situ* cancer*	invasive cancer*	cause of death*
Clinical Diagnosis (i.e. physical examination or radiographic report)	S	S	S	S
Pathological (i.e., histological or cytological) diagnosis	S	S	S	
Death certificate (cancer listed as a cause of death)	S		S	

Notes:
S = This criterion alone is sufficient to report a case.

*All cancers and benign and borderline central nervous system tumors, except basal or squamous carcinoma of skin and *in situ* of cervix uteri and intraepithelial neoplasia, are reportable.

Specific clinical and laboratory criteria for reporting of a case of cancer will be outlined in the Technical Implementation Guide.

C. Disease Specific Data Elements:

Core data elements from laboratories, health care providers, hospitals, or other facilities providing screening, diagnostic, or therapeutic services with respect to cancer are to be included in the initial report. Cancer-specific data elements to be included in the initial report are specified in NAACCR *Volume II, Data Standards and Data Dictionary*, *Facility Oncology Registry Data Standards (FORDS): Revised for 2007*, *SEER Program Coding and Staging Manual*, and CDC-NPCR's *National Program of Cancer Registries Program Manual (Version 1.0).* Incident

cancer cases are reported according to primary anatomic site (topography) and cellular characteristics (morphology including histology, behavior, and grade) using the International Classification of Diseases for Oncology, Third Edition (ICD-O-3).

VII. Case Definition for Case Classification

A. Narrative description of criteria to determine whether a case should be classified as confirmed:

Cancer cases under national public health surveillance include:

- incident invasive cancers at all sites with the exception of basal cell and squamous cell carcinoma of the skin;
- incident *in situ* cancers at all sites with the exception of carcinoma *in situ* of the cervix uteri, or any intraepithelial neoplasia (CIN, PIN, etc.);
- incident benign and borderline central nervous system tumors

A diagnosis of cancer (*in situ* or invasive) or central nervous system tumor (benign or borderline) by a recognized medical practitioner that includes the use of specific terms synonymous with cancer is sufficient for classification as a confirmed case to submit to the appropriate central cancer registry, or the state health department or its designee. These terms include but are not limited to: "cancer," "malignant," "carcinoma," "sarcoma," "leukemia," and "lymphoma." Laboratory-confirmed cases are those that have a positive histology or cytology, or other positive microscopic confirmation. Although more than 90 percent of cancer cases are confirmed microscopically, microscopic confirmation is not required for a confirmed or definite case.

Incident cancer cases are classified according to primary anatomic site (topography) and cellular characteristics (morphology including histology, behavior, and grade) using the International Classification of Diseases for Oncology, Third Edition (ICD-O-3).

B. Classification Tables

Table VII-B lists the criteria that must be met for a case to be classified as confirmed.

Table VII-B. Table of criteria to determine whether a case is classified.

	Cancer/tumor Case Definition		
Criterion	Confirmed		
	Invasive cancers*	In situ cancers*	benign and borderline central nervous system tumors
*Clinical Diagnosis of cancer or CNS tumor**	S	S	S

*Pathological (i.e., histological or cytological) diagnosis of cancer or CNS tumor**	S	S	S
Death certificate (cancer listed as a cause of death)	S		S

** Incident invasive cancers at all sites with the exception of basal cell and squamous cell carcinoma of the skin*
** Incident in situ cancers at all sites with the exception of carcinoma in situ of the cervix uteri, or any intraepithelial neoplasia (CIN, PIN, etc.);*
** Incident benign and borderline central nervous system tumors*

S = This criterion alone is sufficient to classify a case
*All cancers and benign and borderline central nervous system tumors are reportable with the exception of basal or squamous carcinoma of skin and *in situ* of cervix uteri and intraepithelial neoplasia.

VIII. Period of Surveillance

Surveillance should be on-going.

IX. Data sharing/release and print criteria

Notification to CDC of confirmed cases of cancer is recommended.

Each year, central cancer registries submit data for a new diagnosis year to CDC-NPCR and/or NCI-SEER, plus an updated version of previous years' data. Federal agencies in turn update their cancer and benign and borderline central nervous system tumor incidence statistics with each data submission and document the states' date of data submission whenever the data are published. Data products are updated annually, and rules for restrictions on the printing of case data are documented with each data product. A list of data products for data submitted to CDC-NPCR is available at: http://www.cdc.gov/cancer/npcr/datarelease.htm. The list of data products submitted to NCI-SEER is available at: http://seer.cancer.gov/publications/. Since 2002, CDC-NPCR and NCI-SEER have combined their cancer incidence data sources to produce the *United States Cancer Statistics*, a set of official federal cancer statistics. Information about this resource is available at: http://www.cdc.gov/uscs.

For CDC-NPCR, central cancer registries have an opportunity to review their data before each data product is released and have adequate time to notify CDC-NPCR if they identify a problem with the data. Central cancer registries funded by CDC-NPCR have the option to notify CDC-NPCR if they prefer not to have their state data included. NCI-SEER has a separate process for data they receive from their funded state and metropolitan area cancer registries.

For CDC-NPCR, a new submission packet and a new data release policy are reviewed by each central cancer registry prior to submitting data on an annual basis. The data release policy

includes data products for re-release; for data products that are not updated annually, such as WHO, information about these data products are included when necessary. NCI/SEER has a separate process for data they receive from their funded state and metropolitan area cancer registries.

X. References

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