

# **SOUTH CAROLINA CENTRAL CANCER REGISTRY REPORTING SOURCE MANUAL**

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# **I. INTRODUCTION**

## **1. The South Carolina Central Cancer Registry**

The South Carolina Central Cancer Registry (SCCCR) is the population-based cancer surveillance system serving the entire state of South Carolina. The SCCCR is a division of the Office of Public Health Statistics & Information Services (PHSIS) at the Department of Health & Environmental Control (DHEC).

The purpose of the SCCCR is to collect, process, analyze, utilize, and disseminate cancer incidence information. The data are used to study trends in how often and what types of cancers occur in a defined area, to measure cancer incidence and mortality excess in small areas and in sub- population groups, to monitor changes in diagnosis and treatment patterns, and to measure and follow cancer patients' survival patterns. The data are provided for cancer prevention and control efforts and for cancer research in the state and beyond.

## **2. Purpose of This Manual**

Statewide cancer data sources are vital to the success of the SCCCR. Without complete, timely, and highly accurate cancer incidence data from all data sources, the true burden of cancer cannot be measured or addressed. The purpose of this manual is to provide detailed information on the reporting requirements for all statewide cancer data providers. Throughout the manual, useful data links are provided to guide users to standards setters' reference materials that the SCCCR follows. Not all requirements are re-stated in this manual when an easily followed link can be provided. Changes to reporting requirements will be incorporated through updates to the manual and promptly communicated to all reporting sources

## **3. History of the SCCCR – Planning through Implementation**

### **Planning Efforts**

Plans for the development of a statewide cancer registry to track cancer cases date back to the early-1980s in South Carolina (SC). The lack of ability to conduct cancer surveillance in SC was long been recognized and was a major concern of the SC DHEC Cancer Control Advisory Committee (CCAC). Clinicians, epidemiologists, public health professionals, and cancer registrars participated in the central cancer registry planning efforts which were formalized by the CCAC in the mid-1980s.

In 1987, the CCAC appointed a Surveillance Subcommittee to address the lack of statewide cancer reporting. In 1989, the Surveillance Subcommittee recommended the development of a population-based cancer registry to track the incidence of cancer in South Carolina. Initial steps recommended were: 1) to identify funding for the registry; 2) to begin data collection with the American College of Surgeons (ACoS) approved hospitals; 3) to expand to non-registry hospitals, and; 4) to utilize a consultant with expertise in state registry development.

On July 16, 1991, South Carolina was one of four states to be awarded federal funding to develop and implement a statewide breast and cervical cancer control program. The funding was awarded as a five-year cooperative agreement with the Centers for Disease Control and Prevention. A requirement of the cooperative agreement was the establishment of a registry system to collect incidence and stage-at-diagnosis data for breast and cervical cancer. Cooperative agreement funds were available for this activity.

With this funding opportunity, the CCAC Surveillance Subcommittee utilized the services of a consultant to plan for a breast and cervical cancer registry that could be expanded to an all-site cancer registry when additional funds were secured. The subcommittee selected Medical Registry Services, Inc. (MRS) cancer registry software for the Breast and Cervical Cancer Registry software system. The subcommittee also recommended that the breast and cervical cancer registry be housed within the SC DHEC Office of Vital Records and Public Health Statistics (Changed to Office of Public Health Statistics and Information Services) with other statistical and surveillance activities.

### **SC Cancer Registry Steering Committee**

In December 1992, the CCAC established a Planning Committee to organize and structure the SC Cancer Registry Steering Committee to oversee and develop a strategy for future registry activities. The Planning Committee consisted of key DHEC staff, the Chair of the CCAC Surveillance Subcommittee, and the Chair of the CCAC. The Planning Committee solicited representatives of multiple professional organizations, health care facilities, regional cancer registries, physicians, and cancer registrars; all with interest in, and commitment to, cancer reporting.

On January 21, 1993, the first meeting of the SC Cancer Registry Steering Committee was held in Columbia. The following mission statement and objectives were established:

**Promote and enhance the prevention, treatment, and control of cancer in South Carolina by developing and implementing a central cancer registry utilizing existing registry systems.**

Objectives were developed to accomplish this mission. They included:

- 1) develop a statewide population-based data collection system in DHEC for newly diagnosed cancer cases from physicians, hospitals, pathology laboratories, and ambulatory care centers;
- 2) draft statutory requirements and administrative regulations for the protection, collection, and reporting of data to the central cancer registry;
- 3) propose a policy for data access and usage, including research, program planning, surveillance, and dissemination of information;
- 4) develop policies and procedures to ensure confidentiality and the quality and completeness of data;
- 5) recommend and provide consultation on the services the registry will provide, and;

6) identify sources and secure funding for developing and maintaining a central cancer registry.

Three subcommittees were appointed to accomplish the objectives established by the Steering Committee. They included: Legislation, Public Awareness, and Advocacy; Data Usage and Dissemination; and Registry Management and Operations. Chairpersons of the subcommittees were determined by the lead organizations that would champion each effort. The American Cancer Society led the legislative group; the State Data Center's Office of Research and Statistical Services served as leader for Data Usage; and SC Cancer Registrars Association led the Registry Operations effort. These individual subgroups worked diligently during 1993 to achieve the realization of the central cancer registry to be called the SC Central Cancer Registry (SCCCR).

### **Facilities/Regional Registries Agree to Voluntary Reporting to DHEC**

In July 1993, a director was hired of the Breast and Cervical Cancer Registry to coordinate the plan established by the Steering Committee to implement a statewide reporting system. Initial efforts focused on obtaining support of hospitals to submit cancer data to DHEC and to maintain cooperative agreement funding from CDC for implementation of this plan. In the spring of 1994, hospitals were introduced to the idea of reporting data to the SCCCR. Hospitals showed tremendous cooperation through voluntary agreements and submission of 1991-1993 cancer cases. These data were utilized to test systems established within the SCCCR.

The three existing regional cancer registries also demonstrated willingness to participate in the state registry effort. Agreements were obtained with all three: 1) the Savannah River Region Health Information System (SRRHIS), a population-based registry of 13 counties in the Low Country collecting cancer data around the Savannah River Site; 2) the Southern Appalachian Leadership Initiative in Cancer (SALIC) whose coverage area included five counties in the upstate to report their cancer cases to the SCCCR, and; 3) REACH, a federally-funded cancer surveillance project, covering a seven county in the northwestern area of the state. The SCCCR, in turn, helped the regional registries with complete case ascertainment of residents from their respective counties who traveled elsewhere for diagnosis or treatment. This arrangement was mutually beneficial.

### **NPCR Funding Awarded**

In 1994, the National Program of Cancer Registries (NPCR) afforded states the opportunity to apply for 5-year funding through cooperative agreements with CDC to either enhance existing registries or develop and implement a new central registry. In September 1994, SC was awarded 5-year funding as a planning state. The first year was utilized to develop infrastructure, hire staff, and prepare draft legislation to support the operation of the SCCCR. Implementation of full operation of the SCCCR began January 1, 1996. Staff hired at this point included a quality control manager, administrative assistant, a regionally-located data coordinator, and a State-funded data abstractor at 50 percent.

## **Cancer Registry Legislation Developed**

The Legislation, Public Awareness, and Advocacy Subcommittee then began to develop draft legislation to support the operation of the SCCCR and to meet the eight assurances specified in the federal legislation's Cancer Registries Amendment Act, Public Law 102-515. The subcommittee began activities in July 1994 by reviewing existing state legislation, including the statute relating to other health data reporting to the Office of Research and Statistical Services, SC Budget and Control Board, specifically, the Uniform Hospital Discharge Data System. The subcommittee decided this legislation did not include key data elements such as date of initial diagnosis and extent of disease at diagnosis (stage). At that time, only inpatient information was reported. Because of these limitations, the subcommittee recommended DHEC seek additional legislation for the central cancer registry.

Extensive collaboration was conducted with the SC Medical Association (SCMA) and SC Hospital Association (SCHA) to address concerns about reporting additional health data. Meetings were held with individual hospitals and physicians in order to work out solutions to these concerns. The SCCCR staff conducted a pilot data collection project at a small community hospital to demonstrate that there would be little or no burden placed on the small hospitals in order to comply with state cancer reporting. By December 1995, both the SCMA and SCHA had expressed support for the SCCCR and were ready to proceed with a collaborative effort with DHEC and the American Cancer Society (ACS), SC Division for successful passage of cancer registry legislation.

On June 6, 1996, Governor David Beasley signed into law The SC Central Cancer Registry Act of 1996 (amending Title 44, Chapter 35, Code of Laws of South Carolina, 1976) that established the SCCCR and its reporting requirements. The law states that all healthcare providers in SC must report new cancer cases to DHEC according to established national standards. Almost two years later, on April 7, 1998, Governor David Beasley signed into law the Regulation (R.61.45) that detailed the specific rules and reporting requirements supporting The Central Cancer Registry Act of 1996.

## **Implementation of Data Collection and Reporting**

Limited data collection began at non-registry hospitals in the summer of 1996, beginning with the 1996 diagnosis year. Some registry hospitals also began electronic data submissions at this time. However, it was not until June of 1997 that all hospital cancer registry software vendors were able to transmit data to the SCCCR in the required NAACCR record layout. Due to annual changes to this standard record layout for data transfer, the SCCCR experienced delays in registry hospital data submissions.

By November 1998, the first complete year of data collection for diagnosis year 1996 was completed. The SCCCR participated in the NAACCR Call for Data by submitting the 1996 cases for inclusion in the Cancer in North America publication. Death Clearance procedures were not conducted on the initial year of data collection, but were implemented for 1997 data. It was then that the SCCCR data was first examined by the NAACCR Certification Committee for data completeness, timeliness, and quality criteria. Gold Certification was awarded to the SCCCR for the 1997 data.



## II. LAWS AND RULES

### 1. Cancer Reporting Laws

The U.S. Congress established the National Program of Cancer Registries (NPCR) at the Centers for Disease Control in 1992 by enacting the Cancer Registries Amendment Act, [Public Law 102-515 \(PDF-62KB\)](#).

The SC General Assembly passed the [Central Cancer Registry Act SC Law 44-35 \(PDF-71KB\)](#) on June 6, 1996. The Central Cancer Registry Act supports the assurances of Public Law 102-515 and states that all health care providers must report cancer cases to the SCCCR. The Act also ensures that patient confidentiality, as well as physician confidentiality, is protected. Reporting sources who submit data to the SCCCR are also protected from liability incurred through compliance with the state law.

In 1998, the accompanying regulations were passed that outline the specific reporting requirements for the SCCCR. See SC Code of Regulations 61-45.

See Appendix A for copy of state cancer statute and regulations.

### 2. Confidentiality/Security/ and HIPAA

Confidentiality and security policies and procedures are in place in all phases of SCCCR operations to: (1) protect the privacy of the individual patient, (2) protect the privacy of the reporting sources, (3) provide public assurance that the data will not be abused, and (4) abide by the confidentiality-protecting legislation and administrative rules of DHEC that apply.

Health Insurance Portability and Accountability Act (HIPAA) -In 1996 the U.S. Congress passed a law requiring uniform federal privacy protections for individually identifiable health information. This law is called the Health Insurance Portability and Accountability Act of 1996, or HIPAA. The U.S. Department of Health and Human Services (HHS) recently issued final regulations implementing the privacy provisions of HIPAA. These regulations are called the "Privacy Rule". Copies of the HIPAA Privacy Rule, as well as helpful explanatory materials, may be found at the HHS Office of Civil Rights web site: <http://www.hhs.gov/ocr/hipaa/>.

HIPAA guidelines went into effect April 14, 2003. The SCCCR, in the Office of Public Health Statistics and Information Services (PHSIS), is considered a [non-covered entity \(PDF-114KB\)](#) according to HIPAA guidelines. Therefore, HIPAA regulations only minimally impact current state cancer reporting procedures. HIPAA allows for the reporting of identifiable cancer data to public health entities. Because the SCCCR falls under the definition of a public health entity, HIPAA allows facilities and physician practices to continue to report data to the SCCCR in compliance with state law. Written informed consent from each cancer patient reported to public health entities is not

required under HIPAA; rather facilities and physician practices must simply document that reporting has occurred.

The following documents provide further information concerning HIPAA guidelines in relation to cancer reporting:

[Letter from the SCCCR to Reporting Facilities re: HIPAA \(PDF-16KB\)](#)

[Letter from the SCCCR to Physicians re: HIPAA \(PDF-68KB\)](#)

[Academic Letter Interpreting HIPAA from the NAACCR Legal Counsel \(PDF-276KB\)](#)

[FAQs About HIPAA and the Cancer Registry \(PDF-185KB\)](#)

[More FAQs About HIPAA and the Cancer Registry \(PDF-151KB\)](#)

[FAQs About HIPAA for Hospital-Based Cancer Registries \(PDF-44KB\)](#)

### **3. Electronic Exchange of Patient and Cancer Information**

All transfer of cancer patient information between the SCCCR and data sources, between SCCCR staff members or other DHEC staff, or other entities is performed using Web Plus, the secure internet web portal for data transmission provided by CDC. User accounts can be easily set up in Web Plus to facilitate this data exchange. Contact SCCCR Database Manager if a Web Plus account is needed.

Reciprocal Data Exchange Agreements have been established between the SCCCR and other central cancer registries through the National Interstate Data Exchange Agreement System (N-IDEAS) established by the CDC NPCR and North American Association of Central Cancer Registries (NAACCR). These exchanges are all performed utilizing secure means. All interstate exchange generated from the SCCCR is conducted using Web Plus.

## **III. CASE REPORTABILITY**

### **1. Reference Date**

The SCCCR reference date is January 1, 1996. This is the date when population-based cancer data collection officially began in South Carolina Department of Health & Environmental Control (DHEC). All eligible reportable conditions diagnosed on or after this date are to be included in the SCCCR database. The legislation for the central cancer registry was signed into law in 1996.

### **2. Reportable Patients**

All patients first seen at the reporting facility on or after January 1, 1996 (as well as for freestanding/ambulatory surgery centers and freestanding radiation therapy centers), whether as an inpatient, outpatient or in an ambulatory care setting, who meet one or more of the following criteria must be reported:

- a) all patients with an active, malignant neoplasm (in-situ or invasive), whether being treated or not (includes active surveillance),
- b) all patients with an active, benign or borderline brain or central nervous system (CNS) tumor, diagnosed on or after 01/01/2004, whether being treated or not (includes active surveillance)
- c) all patients undergoing prophylactic, neo-adjuvant, or adjuvant therapy for malignancy
- d) all patients diagnosed at autopsy
- e) all historical cases that meet SCCCR reportability guidelines

### 3. Not-Reportable Patients

The following categories of patients are not reporting to SCCCR:

- a) patients seen only in consultation to provide a second opinion to confirm a diagnosis or a treatment plan (no additional testing can be performed at your facility or the case is reportable),
- b) patients in remission (NED) and not receiving prophylactic or adjuvant therapy,
- c) patients first seen at the reporting facility prior to January 1, 1996 and returning after that date for the same primary malignant neoplasm,
- d) patients who receive transient care to avoid interrupting a course of therapy started elsewhere.

### 4. Reportable Conditions - Inclusions

The SCCCR follows requirements of NPCR for reportable conditions as recorded in NAACCR Standards Vol. II.

*Reference Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary, Sixteenth Edition Version 15 – Chapter III: Standards for Tumor Inclusion and Reportability*

#### a) In Situ and Invasive Cancers

SCCCR includes primary malignancies which are in situ and/or invasive. Therefore, any cancer with an ICD-O behavior code of /2 (in situ) or /3 (malignant) is reportable to SCCCR (**except carcinoma in situ of the cervix, CIN III, PIN III and basal and squamous cell cancers of the skin other than genital sites**).

Cancers with benign or borderline behavior are discussed elsewhere in this section. However, if a tumor with an ICD-O behavior code of /0 or /1 is determined to be in-

situ or invasive by the manner in which it is behaving (in malignant fashion), or by a pathologist, the case is reportable.

New terminology may be used by your local pathologist to describe malignant or in situ neoplasms (i.e. well differentiated neuroendocrine neoplasm). When this occurs the neoplasm is reportable to SCCCR.

#### b) Intraepithelial Neoplasia

Anal Intraepithelial Neoplasia (AIN III) is reportable to SCCCR and should be included in casefinding activities. This non-invasive neoplasm of the anus or anal canal (C21.0- C21.1) is not the same as SCC of perianal skin (C44.5). It is important to distinguish between true anal cancers and skin of anus neoplasms. Neoplasms of the skin of anus (perianal skin) are not reportable, even if they extend into the anal canal. AIN III of the perianal skin is not reportable to SCCCR.

Laryngeal Intraepithelial Neoplasia (LIN III) is reportable to SCCCR and should be included in casefinding activities.

Vaginal Intraepithelial Neoplasia (VAIN III) is reportable to SCCCR and should be included in casefinding activities.

Vulvar Intraepithelial Neoplasia (VIN III) is reportable to SCCCR and should be included in casefinding activities.

Pancreatic Intraepithelial Neoplasia (PAIN III) is reportable to SCCCR (histology 8148/2) and should be included in casefinding activities.

Glandular Intraepithelial Neoplasia, Grade III/High Grade Glandular Dysplasia is reportable as adenocarcinoma in situ of the esophagus with histology code 8148/2.

c) In Utero Diagnosis and Treatment – beginning in 2009, diagnosis and treatment dates for a fetus prior to birth are to be assigned the actual date of the event. In the past, those dates were set by rule to the date the baby was born. The exact date may be used for cases diagnosed prior to 2009 and must be used for cases diagnosed 1/1/2009 and later.

#### d) Specific malignant neoplasms of the skin

Dermatofibrosarcoma protuberans, Kaposi sarcoma, malignant melanoma, Merkel cell carcinoma, mycosis fungoides, sebaceous adenocarcinoma, and sweat gland adenocarcinoma are reportable conditions.

Basal and squamous skin cancers in genital sites (histology codes 8000-8110) are reportable. “Genital Sites” include the following anatomic locations:

C51.0 - C51.1 – Labia	C60.0 - Prepuce
C51.2 - Clitoris	C60.9 - Penis
C51.8 - C51.9 - Vulva	C63.2 - Scrotum
C52.9 - Vagina	

e) Other Considerations for Reportability

Gastro-intestinal stromal tumor (GIST) and thymoma are often non-malignant. However, they must be abstracted and assigned a Behavior Code of /3 if they are noted to have multiple foci, metastasis, or positive lymph nodes or there is other evidence of malignancy noted by surgeon, pathologist, or during clinical workup following initial diagnosis.

Chronic Lymphocytic Leukemia patients may exhibit clinical remission (no symptoms) but are never totally free of disease. Physicians may even state these patients are “in remission”. However, these cases should be reported to SCCCR, regardless of physician-stated remission status.

f) Hematopoietic and Lymphoid Neoplasms

The Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the accompanying Hematopoietic Database replaced the February 2001 Single Versus Subsequent Primaries of Lymphatic and Hematopoietic Disease rules and foldout table. An on-line version of the new rules and database is available at: <http://seer.cancer.gov/seertools/hemelymph>. A desktop version is available for download at <http://seer.cancer.gov/tools/heme/>. Please be sure to use the most current version as these rules and codes replace all previous versions. **DO NOT USE ICD-O-3 to code any histology 9590-9992.** Use the Heme Manual and Database.

g) Clinically Diagnosed Cases

Clinically Diagnosed Cases are reportable. In the absence of a histologic or cytologic confirmation of a reportable cancer, accession a case based on the clinical diagnosis (when a recognized medical practitioner says the patient has a cancer or carcinoma or when the patient is undergoing treatment for cancer that may not have been histologically or otherwise confirmed). A clinical diagnosis may be recorded as part of the final diagnosis on the face sheet or other parts of the medical record.

Note: A pathology report takes precedence over a clinical diagnosis. If the patient has a negative biopsy, the case would not be reportable. However, if a clinician treats a patient in spite of a negative biopsy, the case would be reportable.

#### h) Analytic and Non-analytic Case Categories/Class of Case

**The SCCCRCR REQUIRES the collection and reporting of non-analytic cases that meet the SCCCRCR reporting requirements even though the American College of Surgeons/Commission on Cancer (CoC) does not require accredited facilities to abstract non-analytic cases.**

The SCCCRCR calls non-analytic cases “Reportable-to-State-Only Cases”. **See the procedure for *Cases Reportable to State (but not my hospital)* in the Appendix.**

Non-analytic cases may have limited information at the hospital level. The SCCCRCR needs as much information as possible in order to follow back on these cases once received in order to try to determine the correct diagnosis date and tumor information to include in the SCCCRCR database.

This will insure that no cases are missed from being counted (and counted correctly) as incidence cases for the state.

#### i) Benign and Borderline Cancers

Benign and borderline primary intracranial and central nervous system (CNS) tumors with a behavior code of /0 or /1 in ICD-O-3 are reportable as of 01/01/2004. This includes benign and borderline tumors of intracranial glands (pituitary gland, pineal gland, and tumors of the craniopharyngeal duct), meningioma, and tumors of cranial nerves. If the patient has a history of benign and/or borderline intracranial and/or central nervous system (CNS) tumor that was diagnosed prior to 1/1/2004 the case should not be reported to SCCCRCR as a “history of cancer” and should not be sequenced. CDC published a reference manual in 2004 entitled, “*Data Collection of Primary Central Nervous System Tumors.*” The manual is available free of charge in PDF format on the CDC NPCR Website at <http://www.cdc.gov/npcr/pdf/btr/braintumorguide.pdf>. This document and ICD-O-3 are the primary references when determining case reportability for primary brain and CNS tumors. If the diagnosis date of a benign or borderline brain and CNS tumor is unknown and the admission date is 01/01/2004 or later, the case is reportable. Benign and borderline brain and CNS tumors diagnosed prior to 01/01/2004 are reportable as historical cases when accompanied by another reportable primary on or after 01/01/2004. Benign and borderline neoplasms of the cranial bones (C41.0) are not reportable.

Pilocytic/Juvenile astrocytoma is reportable; code the histology and behavior code 9421/3.

Anatomic Intracranial and CNS Sites for Reportable Benign / Borderline Tumors:  
 The CDC Brain Tumor Guide entitled, “Data Collection of Primary Central Nervous System Tumors” is available for reference @

<http://www.cdc.gov/cancer/npcr/pdf/btr/braintumorguide.pdf>

**Reference** *Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary, Sixteenth Edition Version 15 – Chapter III: Standards for Tumor Inclusion and Reportability*

<b>Topography</b>	
<b>Codes</b>	<b>Description</b>
C70.0	Meninges
C70.1	Cerebral Meninges
C70.9	Spinal meninges Meninges, NOS
C71.0	Brain
C71.1	Cerebrum
C71.2	Frontal lobe
C71.3	Temporal lobe
C71.4	Parietal lobe
C71.5	Occipital lobe
C71.6	Ventricle, NOS
C71.7	Cerebellum, NOS
C71.8	Brain stem
C71.9	Overlapping lesion of brain Brain, NOS
C72.0	Spinal Cord, Cranial Nerves, and Other Parts of the Central Nervous System
C72.1	Spinal cord
C72.2	Cauda equina
C72.3	Olfactory nerve
C72.4	Optic nerve
C72.5	Acoustic nerve
C72.8	Cranial nerve, NOS
C72.9	Overlapping lesion of brain and central nervous system Nervous system, NOS
C75.1	Other Endocrine Glands and Related Structures
C75.2	Pituitary gland
C75.3	Craniopharyngeal duct Pineal gland

i) Reportable-by-agreement

SCCCR does not require any additional conditions to be reported ‘by agreement’.

k) Ambiguous Terminology

As part of the registry case-finding activities, all diagnostic reports should be reviewed to confirm whether a case is reportable. This includes pathology reports, bone marrow biopsy reports, autopsy reports, diagnostic imaging reports, and results from medical testing. If the terminology describing the diagnostic assessment is ambiguous, use the following guidelines to determine whether a particular case should be abstracted and reported to SCCCR. Words or phrases that appear to be synonyms of these terms do not constitute a diagnosis. For example, “likely” alone does not constitute a diagnosis. In the absence of more definitive evidence, the following modifying terms, when applied to a neoplasm, should be interpreted as diagnostic of cancer:

apparent(ly)	consistent with	neoplasm*	suspicious (for)
appears	favor(s)	presumed	tumor *
comparable with	malignant appearing	probable	typical of
compatible with	most likely	suspect(ed) *	

\* use of the terms “neoplasm” and “tumor” begin with cases diagnosed 1/1/2004 and later and are to be used in conjunction with nonmalignant (benign or borderline ICD-O-3 behavior codes /0 or /1) primary intracranial and central nervous systems, only (C70.0-C72.9, C75.1-C75.3). “While ‘consistent with’ can indicate involvement, ‘neoplasm’ without specification of malignancy is not diagnostic except for non-malignant primary intracranial and central nervous system tumors.”

Ambiguous Terms That Do Not Constitute a Diagnosis without additional information

The following modifying terms, when applied to a malignancy, should NOT be considered diagnostic of cancer without additional information such as treatment for cancer.

Cannot be ruled out	possible	questionable	suggests
equivocal	potentially malignant	rule out	worrisome

Positive molecular marker or cytogenetic testing in the absence of pathologic or clinical evidence of reportable disease are indicative of risk only and do not constitute a diagnosis.



### In Situ and Invasive (Behavior codes /2 and /3)

If an ambiguous term(s) precede a word that is synonymous with an in situ or invasive tumor (e.g.: cancer, carcinoma, malignant neoplasm, non-invasive cancer, etc.) the case is reportable. Abstract and report the case

Example: The pathology report says: Prostate biopsy with markedly abnormal cells that are typical of adenocarcinoma.” Abstract and report the case.

Negative Example: The final diagnosis on the outpatient report reads: Rule out leukemia. Do not abstract or report the case. Do track that you reviewed the record and deemed the case not reportable. Be sure to include the reason the case is not reportable to SCCCR so you don't have to re-review the case in the future.

Discrepancies: If one section of the medical record(s) uses a reportable term such as “apparently” and another section of the medical record(s) uses a term that is not on the reportable list, accept the reportable term and abstract the case.

Exception: Do not abstract a case based on suspicious cytology, alone. The case is to be abstracted only if proven by positive cytology or other diagnostic method including a physician's clinical diagnosis. See the data item Diagnostic Confirmation for methods of diagnosis.

Note: If the word or an equivalent term does not appear on the reportable list or is not a form of a word on the reportable list, the term is not diagnostic of cancer. Do not report the case. Forms of the word are such as: “Favored” rather than Favor(s); “appeared to be” rather than appears. Do not substitute synonyms such as “supposed” for presumed or “equal” for comparable.

Use these terms when screening diagnoses on pathology reports, operative reports, imaging/scans, mammograms and other diagnostic testing other than tumor markers.

Note: If the ambiguous diagnosis is proven to be not reportable by biopsy, cytology, or physician's statement (cancer was ruled out as diagnosis), do not report the case. Example: Mammogram shows calcifications suspicious for intraductal carcinoma. The biopsy of the area surrounding the calcifications is negative for malignancy. Do not report the case.

Benign and borderline primary intracranial and CNS tumors • Use the “Ambiguous Terms that are Reportable” list to identify benign and borderline primary intracranial and CNS tumors that are reportable.

If any of the reportable ambiguous terms precede either the word “tumor” or the word “neoplasm,” the case is reportable. Abstract and report the case.

Example: The mass on the CT scan is consistent with pituitary tumor. Abstract and report the case.

Discrepancies: If one section of the medical record(s) uses a reportable term such as “apparently” and another section of the medical record(s) uses a term that is not on the reportable list, accept the reportable term, abstract and report the case.

Exception: Do not abstract a case based only on suspicious cytology without additional confirmation of the presence of disease. The case is abstracted and reported if proven by positive cytology or other diagnostic methods including a physician’s clinical diagnosis. See the data item Diagnostic Confirmation for methods of diagnosis.

Note: If the word or an equivalent term does not appear on the reportable list or is not a form of a word on the reportable list, the term is not diagnostic of cancer. Do not abstract the case. Forms of the word are such as: “Favored” rather than Favor(s); “appeared to be” rather than appears. Do not substitute synonyms such as “supposed” for presumed or “equal” for comparable.

Use these terms when screening diagnoses on pathology reports, scans, ultrasounds, and other diagnostic testing other than tumor markers.

Note: If the ambiguous diagnosis is proven to be not reportable by biopsy, cytology, or physician’s statement, do not abstract or report the case.

## 5. Exclusions from Case Reporting

### Skin Cancers

The following site/histology combinations for skin cancers are not reportable:

8000-8004 Neoplasms malignant, NOS of the skin (C44.0-C44.9)

8010-8045 Epithelial carcinomas of the skin (C44.0-C44.9)

8050-8082 Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)

8090-8110 Basal cell carcinomas of the skin (C44.0-C44.9)

ICD- 0-3 C44.0-C44.9 include skin of the lip, eyelid, external ear, face, nose, scalp, neck, trunk, perineum, (peri) anus, umbilicus, upper and lower limbs, shoulders, hips, and skin around ostomy sites.

*Note:* The above lesions ARE reportable when the primary tumor originates in a mucoepidermoid site (See *Reportable Cases* in *SCCCR Manual Part One*).

Skin of nose: Basal and squamous cell carcinomas originating in the external nose (C44.3) are not reportable; however, those primary to the nasal cavity (C30.0) such as nostril, nasal septum, and nares are reportable.

Metastasis from non-reportable sites: If the primary site is not reportable but the cancer has metastasized to other sites, the case is still not reportable.

*Note:* For hospitals with hospital-based cancer registries: According to reporting requirements of the ACoS Commission on Cancer, patients diagnosed with skin cancer (C44. \_) are no longer included in the hospital registry database if the histology is 8000-8004, 8010-8045, 8050-82, 8090-8110. These cases are NOT reportable to the SCCCR.

### **Carcinoma-In-Situ of the Cervix (CIS)**

The diagnosis carcinoma in situ of the cervix (CIS) is not reportable. Terms indicating in situ include: noninvasive, *preinvasive*, *intraepithelial*, and *FIGO Stage 0*. A diagnosis of carcinoma in situ with endocervical gland involvement is still considered in situ and is not reportable.

*Note:* Diagnoses of invasive carcinoma of the cervix ARE reportable. A diagnosis of carcinoma in situ of the cervix with microinvasion is considered invasive and is therefore reportable.

## **6. Patient Address and Residency Guidelines**

The address is the home or residence named by the patient at the time he/she was diagnosed. Legal status and citizenship are not factors in residency decisions. Rules of residency are identical to , or comparable with, the rules of the US Census Bureau whenever possible. Resolve residency questions by using the Census Bureau's definition "the place where he/she lives and sleeps most of the time or the palce the person considers to be his/her usual home." Vital Statistic rules may differ from census rules. Do not record residence from the death certificate. Review each record carefully to determine correct residences. If address at diagnosis is not available, use current address. A post office box is not a reliable source to identify the residency at diagnosis. They do not provide accurate geographical information for analyzing cancer incidence. Use the post office box address only if no street address is available.

NAACCR Layout Version 15: Comparison of Reportable Cancers: NPCR and CoC

	NPCR	COC
<b>Reportable Diagnoses</b>	<p>1. Behavior code of 2 or 3 in ICD-O-3 (includes VIN III, VAIN III, AIN III); or, for 2010 and later diagnoses, behavior code 3 according to the <i>WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues</i> (2008).</p> <p>2. Non-malignant (behavior codes 0 and 1) primary intracranial and central nervous system tumors, including juvenile astrocytoma (M9421/3)* for primary sites as defined in the Table: Primary Site Codes for Non-Malignant Primary Intracranial and Central Nervous System Tumors.</p>	<p>1. Behavior code of 2 or 3 in ICD-O-3; or, for 2010 and later diagnoses, behavior code 3 according to the <i>WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues</i> (2008).</p> <p>2. Non-malignant (behavior codes 0 and 1) primary intracranial and central nervous system tumors, including juvenile astrocytoma (M9421/3)* for primary sites as defined in the Table: Primary Site Codes for Non-Malignant Primary Intracranial and Central Nervous System Tumors.</p>
<b>Exceptions (not reportable)</b>	<p>1. Skin cancers (C44. ) with histologies 8000-8005, 8010-8046, 8050-8084, 8090-8110. 2. CIS of the cervix and CIN III. 3. PIN III (after 1/1/2001).</p>	<p>1. Skin cancers (C44. ) with histology 8000-8110 (after 1/1/2003); prior to that date, AJCC stage groups 2-4 in this group were reportable. 2. CIS of the cervix and CIN III (after 1/1/96). 3. PIN III (after 1/1/96). 4. VIN III (after 1/1/96). 5. VAIN III (after 1/1/96). 6. AIN (after 1/1/96).</p>
<b>Historical Neoplasm</b>	Not included unless patient has evidence of this neoplasm (active disease).	Not included unless patient has evidence of this neoplasm (active disease).
<b>Multiple Primary Rules</b>	2007 Multiple Primary and Histology Coding Rules	2007 Multiple Primary and Histology Coding Rules.
<b>Hematopoietic and Lymphoid Neoplasm Rules</b>	2014 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the 2014 Hematopoietic Database	2014 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the 2014 Hematopoietic Database
<b>Ambiguous Terminology Considered Diagnostic of Cancer</b>	<p>apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of</p> <p>Exception: if the cytology is reported as "suspicious" and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not consider as diagnosis of cancer.</p>	<p>apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of</p> <p>Exception: if the cytology is reported as "suspicious" and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not consider as diagnosis of cancer.</p>
<b>Ambiguous Terminology NOT Considered Diagnostic of Cancer</b>	<p>cannot be ruled out equivocal possible potentially malignant questionable rule out suggests worrisome</p>	<p>cannot be ruled out equivocal possible potentially malignant questionable rule out suggests worrisome</p>

## IV. CASEFINDING

### 1. ICD-9 and ICD-10 Required Screening Codes for Casefinding

The SCCCR utilizes the SEER Casefinding Lists that are updated annually for statewide casefinding. These lists are provided to cancer registrars before year end for the following year's casefinding. The current list can be found at:

[seer.cancer.gov/tools/casefinding/](http://seer.cancer.gov/tools/casefinding/)

### 2. Sources

Casefinding is a system for identifying patients with a reportable malignant diagnosis or condition. All facilities/reporting sources are responsible for COMPLETE casefinding. In many facilities, all records are stored in one location (i.e., health information management department (HIM) or medical records). In others, records may be maintained separately by numerous patient service areas (clinics, departments, etc.). Procedures for identifying patients from numerous independent ancillary service areas may be needed if numerous patient records exist. To maintain an accurate statewide database, casefinding must be timely and complete. The casefinding procedures described should be tailored to meet the needs of each reporting facility.

Cancer incidence can be most accurately reflected only when every reportable case is identified and reported to the central registry. To insure complete coverage of all diagnostic and therapeutic service areas, all applicable sources as described in this section must be reviewed. Cancer Registrar or person responsible for reporting cases to the SCCCR should review all of the following sources:

#### **Health Information Management Department (HIM)**

- a.. Disease Index – Discharges (inpatient, outpatient, ER patient, and ambulatory care or short stay patient) assigned ICD-9-CM codes reflected on the SCCCR Reportable List.
- b. Transcription –All discharge summaries with a final diagnosis of malignancy and/or operative reports bearing a post-operative diagnosis of malignancy may be copied and forwarded to the person responsible for reporting cases to the SCCCR. They serve as a quality control measure for identifying reportable cases.

#### **Laboratory Medicine/Pathology Lab** – Review all of the following:

- a. Histology – Surgical pathology reports\* should be reviewed for a diagnosis of malignant or in situ neoplasm. If your Pathology Department screens the cancer cases and forwards copies of those reports to the person responsible for reporting cases to the SCCCR, this department should be provided with a copy of the *SCCCR List of Reportable Codes/Conditions*. If the Pathology Department provides this information via a text search report, please refer to the NAACCR pathology terminology search list at: <http://www.naacr.org>

Surgical pathology reports showing “no residual malignancy” and reports resulting from orchiectomy or oophorectomy performed for prostate or breast malignancies should be included in the review and copies forwarded to the person responsible for reporting cases to the SCCCR.

- b. Cytology – All cytology reports\* should be reviewed for a malignant diagnosis and a copy forwarded to the person responsible for reporting cases to the SCCCR. An alternative would be to review a log of positive or abnormal cytologies.
- c. Hematology – Peripheral blood reports\* should be reviewed for a diagnosis of malignancy and a copy forwarded to the person responsible for reporting cases to the SCCCR.
- d. Bone Marrow – All bone marrow reports\* should be reviewed for a diagnosis of malignancy and a copy forwarded to the person responsible for reporting cases to the SCCCR.
- e. Autopsy – Final autopsy reports\* should be reviewed for malignant diagnoses and incidental findings of a malignant neoplasm. If the autopsy reports contain reportable diagnoses, the cases should be abstracted and submitted to the SCCCR.

**Outpatient Department** – Review all of the following:

- a. Short Procedure/Same Day Surgery/Ambulatory Care Unit – A system must be implemented to routinely review malignant diagnoses in all outpatient cases maintained separately or within the HIM Department. If reporting criteria are met, cases must be submitted to the SCCCR.
- b. Emergency Room (ER) – Pathology and cytology reports from procedures performed in the ER should be screened and cases reported if a diagnosis of malignancy is made.
- c. Nuclear Medicine – Nuclear medicine reports or logbooks should be reviewed for I-131/thyroid uptake/thyroid scan and any other cases that meet the SCCCR criteria for reportability.

**Oncology-Related Services** – Review all the following when provided by your facility:

- a. Radiation Therapy – Radiation therapy records/appointment logbooks/index cards must be reviewed. If the reporting criteria are met, cases must be submitted to the SCCCR. Patients diagnosed elsewhere but treated at your facility must be reported provided they were first diagnosed after the SCCCR reference date.

- b. Medical Oncology/Chemotherapy – Chemotherapy records/appointment logbooks/index cards must be reviewed. If the reporting criteria are met, cases must be submitted to the SCCCR. Patients diagnosed elsewhere but treated at your facility should be reported provided they are first diagnosed after the SCCCR reference date.

### **Billing Systems**

Unified Billing Systems are used in most facilities to assign charges for services rendered in that facility. These systems utilize diagnostic and procedure codes to assign appropriate charges and may be used as the primary source for case identification. However, other case identification sources (i.e., pathology laboratory reports) **MUST** also be researched to assure complete and accurate casefinding.

### **Other Areas**

Records from other areas of the hospital where cancer is either diagnosed or treated must be reviewed and cases reported if a diagnosis of malignancy is made.

### **Records Maintained Separately from the HIM Department**

Reporting cases when cases are maintained separately from the HIM Department is based on ownership of the medical record. The determination must be made who owns the medical record – whether the hospital or the medical practitioner who only uses space/equipment within the hospital to perform procedures and/or treat his private patients. If the hospital owns the records, the cases must be reported. If the hospital does not own the records, the cases are not required to be reported to the SCCCR but will be accepted if the hospital reports them.

### **Example of Effective Casefinding Procedure**

The most effective approach to identifying all cases reportable to the SCCCR should include the following:

- ❑ Flag all inpatient and outpatient medical records with malignant diagnoses.
- ❑ Review autopsy reports, inpatient and outpatient malignant pathology, cytology, and bone marrow reports including specimens analyzed at your facility as “private outpatients”.
- ❑ Review logbooks for chemotherapy, radiation therapy, and other areas where cancer is diagnosed or treated.
- ❑ Review disease index to identify cancer cases or to verify all cancer cases were reported to the SCCCR.

*Note:* When transmitting electronically, always review your listing of cases accepted by the SCCCR against your accession register.

## Hospitals without Cancer Registries

Hospitals without cancer registries are encouraged to establish cancer registries to facilitate casefinding within their facility. If a hospital does not have a registry, the SCCCR will assist with casefinding and abstracting of cancer cases.

## Pathology Laboratories

The hospital cancer registry staff will perform casefinding in pathology labs in hospitals with cancer registries. All other pathology lab cases are solicited routinely by SCCCR staff to identify reportable cases. The SCCCR has the capability to electronically receive data via a secured electronic site.

## V. REPORTING, ABSTRACTING, AND DATA SUBMISSION REQUIREMENTS

### 1. Methods of Reporting

Hospitals, pathology labs, physician offices and freestanding treatment centers report cancer cases to the SCCCR using one of the following methods:

- a. All Hospitals - Use Electronic Data Submission. Cases are submitted via secure web portal Web Plus by hospitals with hospital-based cancer registries, in current NAACCR Version format. A Web Plus account is set up for each data source.
- b. Pathology Labs: Electronic Pathology (E-Path) reports - Submission of electronic pathology reports is instituted by the SCCCR in order to capture those cases that may not reach the traditional hospital setting. Cancer pathology reports are submitted electronically using a nationally adopted uniform communication protocol developed by the NAACCR Pathology Lab Subcommittee, NAACCR Standards Volume V. Reports are submitted in either a text file or HL-7 file format. Transfer of the electronic pathology reports to the SCCCR occurs via PHIN-MS messaging to DHEC.
- c. Physician offices - Confidential Cancer Reporting Form may be used or Web Plus if electronic reporting is feasible.

Electronic Transmittal of confidential data to the SCCCR must occur only through the secure web portal Web Plus. Email password-protected files are not acceptable. If a data source chooses to do so, they may fax the Confidential Cancer Reporting Forms to the SCCCR confidential fax.

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### 2. Submission Guidelines

- a. Complete Cases - Registry Hospitals and SCCCR staff must submit abstracted data to the SCCCR via Web Plus. Data must be submitted in **NAACCR Data Exchange Record Layout for Record Type A**, found in NAACCR Standards for Cancer Registries edition that is applicable to date of initial diagnosis., (see [www.naaccr.org](http://www.naaccr.org) for table). **Record Type A** is a full case abstract record type including text summaries.



- b. Reportable-to-State Only Cases - Cases with reportable codes that are not abstracted into the registry hospital's database must be reported to the SCCCR. These are called Reportable-to-State cases. Hospital registries may abstract these cases into the database as an "N" or "R" case. These cases must be submitted to the SCCCR **SEPARATE** from the Complete cases. This is extremely important as SCCCR registry software accepts only Complete cases and does not differentiate Reportable-to-State cases.

Registry Hospitals must submit this separate submission via Web Plus. Data must be in current **NAACCR Data Exchange Record Layout for Record Type A**, found in NAACCR Standards for Cancer Registries edition that is applicable to date of initial diagnosis., (see [www.naaccr.org](http://www.naaccr.org) for table). **Record Type A** is a full case abstract record type including text summaries.

### 3. Reporting Frequency for Facilities – Medium and Large Case Volume

- a. Facilities with medium case volume, < 500 cases annually, must report at least quarterly to the SCCCR.
- b. Facilities with large case volume, > 500 cases annually, must report monthly to the SCCCR.

### 4. Timeliness of Case Reporting (also see Quality Control Section)

Cancer cases must be submitted to the SCCCR within 7-9 months after diagnosis. **Standard:** The CDC National Program of Cancer Registries (NPCR) requires 90% of expected unduplicated invasive cancer cases to be included in the central registry within twelve months of the close of the diagnosis year.

The SCCCR Expected Completeness Table is used to measure timeliness of reporting from registry hospitals. Expected Completeness is monitored using the SCCCR Quarterly Report for Completeness, Timeliness, and Quality.

The SCCCR Quarterly Report for Completeness, Timeliness, and Quality is provided back to each facility at the end of each quarter with percentages of actual reported cases to the expected, resulting in an expected completeness percentage. This information helps the SCCCR know which facilities are current with reporting as well as alert the hospitals of any problems, or that they are doing a great job.

### 5. Required Data Items for Reporting

The SCCCR follows NPCR standards for required data items. These can be referenced in the NAACCR Required Status Table in NAACCR Standards Volume II, Chapter viii, at [naaccr.org/LinkClick.aspx?fileticket=mBvcfaL-lfs%3D&tabid](http://naaccr.org/LinkClick.aspx?fileticket=mBvcfaL-lfs%3D&tabid)

The SCCCR communicates any changes in data item requirements annually to statewide registrars. There are no 'state-specific' data items required by the SCCCR.

## **6. Case Abstracting**

Individual cases must be abstracted no later than six months after the date of initial diagnosis or first contact with the reporting source/facility. Cases may be abstracted earlier than six months after the date of initial diagnosis or first contact, but only if the required information regarding first course treatment/therapy is available and complete. (i.e. patient expired, no extended therapy)

The SCCCR requires analytic and non-analytic cases to be reported. Although the CoC does not require accredited facilities to abstract non-analytic cases, a population-based cancer registry such as SCCCR must record ALL cancers meeting the SCCCR reporting requirements, regardless of class of case, place of diagnosis or date of diagnosis. Much of the information about the original diagnosis, staging and treatment of non-analytic cases may be sketchy. The abstractor should attempt to complete each abstract with as much information as is available in the medical record.

### **Overview of Cases to be Reported to SCCCR (not required by CoC):**

In an effort to ensure that all incident cancer cases are identified correctly in SC, the following cases are required to be reported. Note: These cases should be abstracted if as "Reportable-to-State-Only" and must be submitted separately from the registry data submission to the SCCCR.

**Non-analytic cases:** out of state residents, patients seen for subsequent treatment, patients with no evidence of active cancer, history of cancer with no treatment at present time

**Consult cases:** patients seen only for consultation or second opinion, pathology specimen only (Class of Case 7)

**Cases diagnosed prior to 1996\*:** patients diagnosed prior to the reference year of the SCCCR

**Blood disorders prior to 2001\*:** these conditions that became reportable in 2001 (238.4, 238.6, 238.7, 284.9, 285.0, 288.3, and 205.1 9963/3)

**\*These categories of cases will eliminate repetitive chart review during casefinding for SCCCR and hospitals.**

## **7. Changes to Abstracted Information and Resubmission of Cases**

A change includes updating or correcting previously submitted information. The change procedure ensures the most accurate information is available to users of SCCCR data by enabling reporting facilities to provide updated or corrected information after a case has been accessioned by the SCCCR.

*Example:* At the time a case was reported to the SCCCR, the primary site was unknown. On a subsequent admission, the primary site was documented as upper lobe of left lung.

*Example:* At the time a case was reported to the SCCCR, the patient's initial diagnosis was *probable carcinoma*. After further review, it was determined the patient does not have cancer. Such cases must be deleted.

If a Major Data Item is changed or corrected in the Hospital Database, the hospital must re-submit that case.

Major Data Items include: Patient's name, date of birth, social security number, behavior, histology, date of diagnosis, summary stage, primary site, sequence, laterality, address at diagnosis, diagnostic confirmation, race, sex, diagnosis county and date of death.

Note: Submit a change for name when incorrectly spelled on record and when name is changed due to marital status or other reason. Do not submit changes to update address changes or admission/discharge dates when the patient is readmitted.

Registry software requires a flag to be flipped or an X to be removed from the data field that will allow this case to be resubmitted along with routine data submissions

## **8. Guidelines for Abstracted Text**

Text is required by the SCCCR to be reported to substantiate coded data items. Guidelines for abstracted text are provided in ***Quality Control Section, 7. Text Requirements.***

## **9. Determining Multiple Primary Cancers**

The SCCCR requires NCI SEER multiple primary rules be applied to all reported cases. This is in accordance with standards set forth by CDC's National Program of Cancer Registries (NPCR). For Multiple Primary and Histology (MP/H) Rules refer to: <http://seer.cancer.gov/mphrules>

# **VI. QUALITY CONTROL**

## **1. Timeliness, Completeness, and Quality Standards**

Quality control procedures must be in place to ensure cancer data reported to the SCCCR are timely, complete, and accurate.

Timeliness – Cases must be completed within 180 days of discharge or outpatient treatment date. A monitoring system should be in place to identify cases not complete after five months from discharge so appropriate steps could be taken to report within the 180-day time frame. The SCCCR monitors timeliness of reporting on a quarterly basis (at the end of each quarter, so that cases should be reported to the SCCCR within 7-9 months after diagnosis/discharge).

Completeness - Completeness is the extent to which all required cases have been reported to SCCCR. Make sure all areas where cancer patients are diagnosed or treated are included in the casefinding system. This includes autopsy and private outpatient specimens. Periodically check the inpatient and outpatient disease indices to make sure all reportable cases have been included. Completeness is monitored on a quarterly basis as described further in this section.

Accuracy – Accuracy is the extent to which the data submitted have been correctly coded and match the information contained in the medical record. Accuracy encompasses correct interpretation and application of coding rules and guidelines, identifies data entry and data submission errors and evaluates case correctness. Make sure all required data fields are complete, accurate, and include appropriate text.

The SCCCR standard for data quality requires 90% of all submitted abstracted to be edit-free. Hospital software must contain the SC Edit Set provided by the SCCCR in addition to any other edits provided by the vendor. The Web Plus Edit Set runs on all data submitted to the SCCCR. Edit reports are available from Web Plus for the results of these edits.

Quality in the SCCCR database is monitored through internal computerized edits, visual review of codes and text, and quality assessment reviews. These methods are essential for achieving a quality dataset to determine the true cancer burden on the citizens of South Carolina. The quality control activities conducted by the SCCCR staff in conjunction with reporting facilities may be utilized to meet hospital's quality control requirements when appropriate. The quality control review assesses casefinding completeness, timeliness of reporting, and accuracy of information reported.

These quality control edits and reviews are not performed to “criticize” a reporting facility; instead they will be used to identify areas where a good job is being done consistently and where there is a need for improved abstracting standardization or specific training. This enables facility personnel to be aware of potential areas of concern or compliance related to other related surveys.

## **2. Quarterly Review of Data Submissions/Feedback to Facilities for Timeliness, Completeness, and Data Quality**

Quarterly Report of Timeliness, Completeness, and Quality - All registry hospital data submissions are monitored for these three important components. This report is

generated at the end of each quarter and provided to each registry hospital. The purpose and explanation of the report are described below:

**Purpose:** To provide information back to each registry hospital on a quarterly basis regarding their data submissions to the SCCCR. A summary of timeliness of reporting, completeness of reporting, and data quality of each submission is provided.

**Explanation of Report:** The Report contains three tables:

- 1) Completeness and Timeliness of Reporting: Case Counts/Percent Complete**
- 2) Data Quality: Quarterly Activity Summary**
- 3) Completeness of Reporting: Monthly Case Submission Summary(byDODx)**

Each table is created as follows:

**Completeness and Timeliness of Reporting -**

- a. *Case count* - The annual case count (from CRS Plus) for the past 5 years.
- b. *Average Cases Reported* - The average number of annual cases reported is calculated using the most recent 3 years of data completed. That number is the basis from which completeness is assessed.
- c. *Percent Complete ACTUAL* – Calculated for the two current years of data collection (e.g., 2014, 2015) by dividing the Case Count for the year of interest by the average of cases reported (Case count/Avg Cases Reported).
- d. *Percent Complete EXPECTED* – Based on the reporting schedule facilities should follow to report cases to SCCCR (See EXPECTED COMPLETENESS TABLE attached)

**Data Quality: Quarterly Activity Summary –**

- e. *# Abstracts submitted* – Sum of all submitted abstracts for quarter
- f. *# Abstract with 0 EDITS* – Sum of all submitted abstracts for quarter with no EDIT errors (source: PrepPlus Edit Details Report.)
- g. *# Abstracts with EDITS* – Sum of all submitted abstracts for quarter with EDIT errors (source: PrepPlus Edit Details Report)
- h. *# Abstracts Rejected* – Sum of individual abstracts that failed EDITS and were rejected back to facility (source: WebPlus report)

**Completeness of Reporting: Monthly Case Submission Summary (by Date of Diagnosis) –**

- i. Quarterly summary of cases submitted *by month of diagnosis* for last two consecutive reporting years to demonstrate the level of completeness for current reporting year compared to previous year.
- j. Quarterly totals provided for the last two consecutive reporting years by *month of diagnosis*.

### 3. Schedule for Case Reporting

Cases should be reported to the SCCCR 7-9 months after diagnosis, given the 6-month rule for completing abstracts on cases 6 months from the time of diagnosis/first contact. **Therefore, each quarter, 25% of cases are due to the SCCCR from facilities.**

These time frames and expected completeness percentages are reflected in the Expected Completeness Table that follows:

**EXPECTED COMPLETENESS TABLE**

<b>Hospital Cases by Month of Dx.</b>		<b>Due to SCCCR</b>		<b>Expected Annual Complete %</b>
Jan – Mar		Oct – Dec (same year)		25%
Apr – Jun		Jan – Mar (following year)		50%
July – Sept		Apr – Jun (following year)		75%
Oct – Dec		July – Sept (following year)		100%

### 4. SCCCR EDITS

The SCCCR runs electronic EDITS via Web Plus on all incoming records submitted from all data sources. SCCCR provides facilities with the same EDITS that are used at the SCCCR for quality control of incoming data. The SCCCR provides new EDIT Metafiles to each software vendor as they are released so that they can be incorporated at the facility level prior to the SCCCR upgrade of Web Plus software. The timing of the new EDITS implementation is set up so that they occur at the facility first. Therefore no records will be flagged with edits that the facility is not aware of.

Prior to 2014, acceptance of each bundle of uploaded records was based on an EDIT threshold of 20% or lower, i.e., if 100 records were submitted, 20 records or less could contain edits in order to be accepted.

In January 2014, the EDIT threshold was revised to 10% (or lower). Therefore, if 100 records are submitted, 10 records or less within the bundle can contain edits. Otherwise, the bundle of 100 records will be rejected until the edits are corrected, then the bundle must be resubmitted.

The SCCCR requires facilities to check the Web Plus Error Detail Report prior to each data submission to eliminate any edits before submission to the SCCCR. They should also run Gen EDITS prior to each data submission to resolve any edits.

The standard computerized data edits check for item validity, internal consistency, and inter-record consistencies. The edit checks include single-field edits (to check for valid codes), multi-field edits (to check for consistency and logic between different fields), multi-record edits (to check for consistency between multiple sequences and multi-database edits (to check for consistency between different hospitals seeing the same patient for the same tumor). A complete list of these edits may be obtained from the SCCCR upon request.

## 5. Audits/Quality Studies

### Casefinding Studies

Casefinding studies are performed to measure the completeness of case ascertainment within the SCCCR. At least one study will be performed each year by the SCCCR to determine completeness of case ascertainment. These may not be 'formal' casefinding studies that require visits to facilities, but can be performed through electronic means, comparing casefinding lists, pathology lab cases, etc., to submitted cases from facilities.

**Standard**-95% of expected unduplicated cases of invasive cancer occurring in SC residents in a diagnosis year are reported to the SCCCR. An expected number of cases for each reporting facility, each SC county and the state is calculated according to established methods used to measure completeness of reporting.

Various studies may include, but are not limited to the following:

- ❑ Comparison of (an) independent methods(s) of case ascertainment with cases reported routinely, generating an estimate of percent completeness
- ❑ Analysis of the location of the medical record for cases that were first identified by death certificate follow-back
- ❑ Special studies to analyze the effect of including or excluding certain possible sources of cancer case identification on the completeness of case ascertainment (e.g., study to assess the impact of ignoring radiation logs, or gynecology cytology's, etc.)
- ❑ Surveys of medical practitioners who might diagnose a reportable cancer outside of the usual sources of case identification (e.g., dermatologists who read their own slides; out-of-state pathology laboratories that handle specimens from the registry's area)
- ❑ Other study designs may be developed specific to SC case ascertainment needs

### Reabstracting Studies

The objective of a reabstracting study is to characterize the level of agreement between data already in the registry and data reabstracted from source records (i.e., medical

records) by Quality Control Editors. SCCCRC will perform reabstracting studies to retrospectively assess accuracy and reproducibility of the registry data.

**Standard** - a minimum of 5% of annually reported cases within the SCCCRC database will be reabstracted.

Selected data items from the randomly chosen medical records will be reabstracted and compared to the original abstract. Any discrepancies found will be classified as major or minor discrepancies according to SEER Major-Minor Discrepancy Definitions as listed in the NAACCR Standards for Cancer Registries Volume III. The results of these studies will be analyzed using the suggested item-specific agreement rate standards for reabstracting studies as found in the NAACCR Standards for Cancer Registries Volume III. Modifications to these standards will be refined as the SCCCRC develops SC specific confidence limits.

### **Recoding Studies**

Recoding studies help characterize the level of agreement between SCCCRC data and data recorded from actual abstracts by QC Editors. This method retrospectively assesses coding accuracy and reproducibility in cancer data. It also removes abstracting differences from the interpretation of the medical record as a possible source of code discrepancy as may occur in reabstracting studies.

**Standard** - Recoding studies will be performed on a minimum of 5% of data submitted to the SCCCRC. Major-Minor discrepancies will be identified and compared to the SEER/NPCR agreement standards as in the reabstracting studies.

### **Abstracting and Coding Reliability Studies**

Reliability studies will not be scheduled as a routine SCCCRC quality control study; but may be used as an accessory study for the quality control program. Reliability studies involve test cases being abstracted and/or coded by different abstractors throughout the SCCCRC reporting facilities.

Depending on the study design, this method can assess the measure of agreement between abstractors, the data entry process and possible limitations in various software systems.

## **6. Linkages**

The SCCCRC will further quality control efforts of the central cancer registry database through data linkages with various external sources of information. These linkages will provide identification of missing data elements not available to the reporting facilities at the time of abstraction, street/city/county information and potential missed cases. Feedback to the reporting facilities of any pertinent findings will improve the quality of the hospital and central registry databases.

**Death Match** – Death clearance is an essential step in achieving complete population-based reporting. It serves as a check on completeness of reporting and often identifies missed cases. Death match is a data linkage of SCCCRC database to the DHEC Vital



Records Death Files. It is conducted annually. When the SCCCR database is considered to be at least 85% complete and the SC Resident Death File is complete for that year, the record linkage is performed.

Potential cases still considered Death Certificate Only cases after follow-back procedures are completed, will be added to the SCCCR database. In addition, death information added to cases in the SCCCR database as a result of death clearance will be provided to reporting facilities to enhance patient follow-up efforts.

**Hospital registries are critical to the follow-back efforts for death clearance. Lists of non-matched deaths resulting from the Death Clearance Match are sent to appropriate facilities to obtain any additional clinical information to confirm the cancer listed on the death certificate and the date of diagnosis.**

**Standard** – The percentage of cases diagnosed by Death Certificate Only must be less than 3% of all cancers registered in a given year after follow-back, according to NAACCR and NPCR Standards.

**GIS** – (Geographical Information Systems). GIS within the DHEC Office of PHSIS is utilized to assign geographic characteristics to SCCCR cases. The GIS program pinpoints cases and can be used to provide special characteristics to health data. Linkage between the SCCCR database and GIS will help identify and effectively demonstrate potential cancer clusters for investigation in SC. GIS will also assist in standardization of address information recorded on cancer abstracts. **Therefore, accuracy in reporting patient address is important so that geocoding is correct for SC cancer cases.**

**Other State Registries** – Reciprocal Data Exchange Agreements have been established between the SCCCR and the central cancer registries of other states. Linkage with these registries can provide identification of SC residents who may be diagnosed and treated outside of SC, or who died in another state. It can help reduce the number of DCOs in the database.

**RFA (formerly ORS)** – The SC Revenue and Fiscal Affairs (RFA) Office, formerly the Office of Research and Statistics (ORS), in the SC Dept of Administration provides useful information for SCCCR quality control linkage. RFA houses the SC Hospital Discharge Data System, all in-patient and most out-patient hospital Uniform Billing information. These data can be used as a cancer case ascertainment check when linked to the SCCCR database. SCCCR staff will perform casefinding on RFA cancer cases not found in the SCCCR database to determine if they are incident cases to be included in the SCCCR. This quality control check can be beneficial to the reporting hospitals for identifying missed cases.

## **7. Text Requirements**

Text is considered necessary to justify the codes chosen for the data items and to allow recoding information that is not coded at all. It is a component of a complete electronic abstract, and allows for the full abstract to be printed or reviewed on the screen as needed. The text is used for quality control and special studies. As the purpose of text

information is to provide an opportunity for documenting and checking coded values, information documenting the disease process should be entered from the medical record and should not be generated electronically from coded values.

Any additional text that may be relevant to the cancer patient's abstract, must be submitted. This includes any statements or reports by a recognized medical practitioner that aided the abstractor in determining specific coding. Alternatively, this text may provide other pertinent information not required for submission; however might clarify the patient's overall "cancer picture".

**Documentation MUST be entered** to substantiate the coding of various data items.

The documentation of diagnostic, surgical, and imaging procedures is essential for the justification of selections in coding primary site, histology, and staging. This is a very important segment of the abstract. **Ample text is REQUIRED to support the coding of the data items.**

*Note:* For systems that allow unlimited text, NAACCR recommends that it be indicated to abstractors in reporting facilities how much of the text will be transmitted in a data exchange record so that they can prioritize data entry to ensure that the most important information is sent to the central registry.

The use of standard abbreviations in the diagnostic text is strongly recommended.

Refer to *SCCCR Manual Common Approved Abbreviations*.

*Note:* Sufficient text MUST be entered to document and substantiate the coding of ALL of the following items:

**NAACCR Item Name**

Text – DX Procedures – Physical Exam

Text – DX Procedures – X-Ray/Scans

Text – DX Procedures – Scopes

Text – DX Procedures – Lab Tests

Text – DX Procedures – Operative Report

Text – DX Procedures – Pathology Report

Text – Primary Site Title

Text – Histology Title

Text - Behavior

Text - Grade

Text – Staging

RX Text – Surgery

Enter text information from:

- History & physical examinations: duration/type of symptoms, location of tumor, family history, etc.
- Diagnostic imaging reports, including X-rays, CT, MRI and PET scans, ultrasound and other imaging studies.
- Endoscopic examinations. Information can include visualization of tumor, location of tumor, etc.

- ❑ Laboratory examination: tumor markers, serum and urine electrophoresis, special studies, etc.
- ❑ Tumor Markers can be obtained from serum, immunostaining, tissue and other specimens. They may be cancer-specific or more general involving markers for numerous cancer types. Some tumor marker examples include:  
Breast Cancer: Progesterone Receptor Assays (PRA), Estrogen Receptor Assays (ERA), Her2/neu  
Prostate Cancer: Prostatic Specific Antigen (PSA)  
Testicular Cancer: Human Chorionic Gonadotropin (hCG), Alpha Feto Protein (AFP)  
Liver Cancer: Alpha Feto Protein (AFP)  
Ovarian Cancer: CA-125  
Other Markers: Carcinoembryonic antigen (CEA)-Colorectal, CA-19-9, BRCA , etc
- ❑ Operative reports: tumor size, extent of involvement of primary or metastatic sites not surgically excised or biopsied and other information that may not be documented elsewhere.
- ❑ Cytology and histopathology reports: tumor size, extent of tumor spread, involvement of resection margins, tumor type and grade, etc.
- ❑ Surgical procedure(s) performed as part of first course of therapy.

## VIII. SCCCRC EDUCATION/TRAINING

The SCCCRC does not have a dedicated training coordinator on staff responsible for educational endeavors. The SCCCRC collaborates with the Florida Cancer Data System (FCDS) for education/training activities. The FCDS provides educational opportunities in various formats throughout the year. Education focuses on state reporting requirements as they relate to all applicable registry standards. Some of the training is designed for health care personnel who are newly responsible for reporting to the SCCCRC. Training is web-based and free of charge whenever possible.

The SCCCRC works closely with the Education Committee of the SC Cancer Registrars Association on assessing training/educational needs for the membership. Education surveys are conducted on a routine basis to gather feedback on what the needs are for upcoming planning of activities.

Announcements listing dates and locations of scheduled training are electronically mailed to SCCCRC contacts. Anyone interested in attending training must be sure the SCCCRC has current email address information. **The SCCCRC phone numbers are 1-800-817-4774 or 803-898-8000.**

## IX. DEATH CLEARANCE

Death Clearance is a required procedure carried out annually in order to assess missed incident cases that are identified by linking to the SC Vital Records death files, and to add death information to the SCCCRC database for existing incident cases. Death Clearance procedures include Death Match and Death Clearance Follow back.

## **1. Death Match**

The death file is matched against the SCCCR database to determine the deaths that match to incident cases in the SCCCR database. The cause of death is checked against the primary sites as well as any of the distant sites in the SCCCR database to help determine if the patient died of the cancer reported to the SCCCR. The text in the abstract may provide enough information to “clear” the death.

## **2. Death Clearance Follow Back**

The remaining deaths are considered non-matched deaths and must be followed back to obtain information to confirm the cancer and the date of diagnosis from a medical practitioner.

A listing of the non-matched deaths is sent to each facility’s cancer registry. For deaths from hospitals collected by the SCCCR staff, a listing is sent to the SCCCR CTR abstractor assigned to that facility.

Hospital cancer registrars/SCCCR abstractors must search for information to confirm the cancer listed on the death certificate and the date of diagnosis. This information is provided back to the SCCCR Database Manager responsible for Death Clearance within the established timeline.

With sufficient information on the confirmation of the cancer and date or estimated date of diagnosis, the case can be added to the SCCCR database as an incident case in the appropriate year of diagnosis.

If sufficient information cannot be provided and the only information on the case is from the death certificate, the case must be entered into the SCCCR database as a Death Certificate Only (DCO) case. These cases are not meaningful cases to be used in analysis due to incomplete information. So the goal is to minimize the number of DCO cases in the database.

Assistance of hospital registrars is critical in completing this cancer registry operation. Analysis of the missed incident cases by the central registry helps to determine reasons the cases were not reported initially at the time of diagnosis. Additional data sources may be identified.

## **X. DATA RELEASE AND OTHER USES**

### **1. The Principles and Protocol for Data Release from the SCCCR**

This document outlines the principles for protection of restricted SCCCR data and the steps for gaining approval to access SCCCR data for use. The document can be accessed on the SCCCR Website. Instructions are also provided for researchers or other users who will need to complete the SCCCR Data Application to request data for release. The DHEC Cancer Control Advisory Committee’s Surveillance Subcommittee is responsible for review of all data applications for restricted data. This subcommittee

serves as the advisory committee to the SCCC. Contact SCCC Assistant Director for information about requesting SCCC data.

## **2. Annual National Calls for Data**

- a. NAACCR Call for Data – includes a Combined Data File of all years of registry data to be used in the Cancer in North America (CINA) publication. Also, the most recent Data Year File is submitted. Certification is determined from this file at Gold or Silver Certification levels.
- b. NPCR CSS – All data through the most recent 12 month period are submitted to NPCR. National Data Standards criteria and Levels of Excellence are measured on this file at the 24-month level and 12-month level. Determination of inclusion in the United States Cancer Statistics publication is provided via this data submission.

Certification and National Data Standard criteria are available upon request from the SCCC.

## **XI. MEANINGFUL USE OF ELECTRONIC HEALTH RECORDS FOR CANCER REPORTING**

Submission of cancer cases and treatment data to public health agencies electronically is one of the options to demonstrate meaningful use (MU) of electronic health records (EHR). Cancer reporting from ambulatory providers to state cancer registries is a public health objective for MU Stage 2.

Reporting to cancer registries through this method by health care providers could address under-reporting of cancer, especially certain types. In the past most cancers were diagnosed and/or treated in a hospital setting and data were primarily collected from this source. However, medical practice is changing rapidly and an increasing number of cancer cases are never seen in a hospital. Data collection from providers presents new challenges since the infrastructure for reporting is less mature than it is in hospitals. Certified EHR Technology can address this barrier by identifying reportable cancer cases and treatments to the provider and by facilitating electronic reporting either automatically or upon verification by the provider.

The electronic reporting of cancer cases and treatment data fulfills South Carolina's cancer reporting requirements. Messaging from ambulatory providers meets the MU objective.

Data submission is coordinated from DHEC. Submissions to this central point are disseminated to the appropriate health personnel within public health using centralized data systems with role-based access.

Sending information to DHEC electronically does not by itself satisfy the MU criteria. The information must be sent in specific formats that have been developed to send health-related information between health care information systems. DHEC is currently

establishing its submission format for Cancer Registry Data. For cancer registry data reporting contact: [CancerRegistryMU@dhec.sc.gov](mailto:CancerRegistryMU@dhec.sc.gov) or call (803) 898-8000.

## APPENDIX A

### SC CENTRAL CANCER REGISTRY ACT AND REGULATIONS

#### CHAPTER 35.

#### CANCER

**SECTION 44-35-5.** Short title.

Sections 44-35-10 through 44-35-100 may be cited as the Central Cancer Registry.

**SECTION 44-35-10.** Formulation of plan for cancer prevention, detection, and surveillance programs.

The Department of Health and Environmental Control, in conjunction with hospitals and entities throughout the State, shall formulate a plan for cancer prevention, detection, and surveillance programs and for care of persons suffering from cancer to meet standards of care set forth by nationally recognized and approved accrediting bodies.

**SECTION 44-35-20.** Establishment, administration, and purpose of central cancer registry.

(A) There is established the South Carolina Central Cancer Registry and, to the extent funds are available, the Department of Health and Environmental Control shall administer this as a statewide population-based registry of cancer cases with a diagnosis date after December 31, 1995.

(B) The purpose of the registry is to provide statistical information that will reduce morbidity and mortality of cancer in South Carolina. This information must be used to guide cancer control effort in the State by assisting in prevention and early detection of cancer, extending the life of the cancer patient, identifying high-risk groups or areas in the State with cluster of cancer cases, and improving cancer treatment.

(C) The registry shall receive, compile, analyze, and make available epidemiological and aggregate clinical cancer case information collected from all health care providers who diagnose and/or treat cancer patients in this State. The registry shall meet national standards of completeness and timeliness of case reporting and quality of data. Annual reports of aggregate cancer data must be provided to reporting facilities and physicians in the State.

**SECTION 44-35-30.** Reporting requirements; applicable regulations.

(A) A provider who diagnoses and/or treats cancer patients and does not report to a regional cancer registry shall report specific case information to the registry in accordance with regulations promulgated by the Department of Health and Environmental Control. These regulations shall include, but are not limited to, the reportable case listing, data elements to be collected, the content and design of forms and reports required by this section, the procedures for disclosure of information

gathered by the registry, and other matters necessary to the administration of this section. The regulations shall include these data elements:

- (1) complete demographic information;
- (2) occupational and industrial information to the extent available;
- (3) date and confirmation of initial diagnosis;
- (4) pathological information characterizing the cancer, including cancer site and cell type, stage of disease, and initial treatment information, to the extent available, in the medical record.

A provider participating in a regional registry is not required to report to the Central Cancer Registry. Reporting providers must not incur additional expense in providing information to the registry.

(B) Regional registries shall report data on behalf of providers in their area to the Central Cancer Registry.

**SECTION 44-35-40.** Confidentiality; data release protocol.

Information that could identify the cancer patient must be kept strictly confidential in accordance with the administrative policy of the Department of Health and Environmental Control. This information must not be open for inspection except by the individual patient or the patient's authorized representative. Procedures for the disclosure of confidential information to researchers for the purposes of cancer prevention, control, and research must be promulgated in regulations. The data release protocol developed in coordination with the South Carolina Budget and Control Board, Office of Research and Statistical Services, must be utilized by the registry to determine appropriate use and release of cancer registry data.

**SECTION 44-35-50.** Coordination of collection and report of cancer data.

The registry shall coordinate, to the fullest extent possible, with the State Budget and Control Board, Office of Research and Statistical Services, for the complete, timely, and accurate collection and reporting of cancer data.

**SECTION 44-35-60.** Immunity from civil or criminal liability.

A provider or regional registry making a case report or providing access to cancer case information to the registry is immune from any civil or criminal liability that might otherwise be incurred or imposed.

**SECTION 44-35-70.** Acquisition of laboratories, hospitals, or other property.

The Department of Health and Environmental Control may, to the extent of and within the available funds which may be provided, acquire laboratories, hospitals, or other property, either real or personal, by gift, purchase, devise or otherwise, as the department considers advisable to afford proper treatment and care to cancer patients in this State and to carry out the intent and purpose of this chapter.

**SECTION 44-35-80.** Discretionary aid to cancer patients.

The Department of Health and Environmental Control may furnish aid to cancer patients who are residents of this State to the extent of and within the available funds as the department considers proper. The department may administer this aid in any manner



which, in its judgment and with the approval of the Cancer Control Advisory Committee, provided for in Section 44-35-90, will afford greater benefit for the prevention, detection, and control of cancer throughout the State.

**SECTION 44-35-90.** Powers, duties, and purpose of Cancer Control Advisory Committee.

There is established within the Department of Health and Environmental Control the Cancer Control Advisory Committee. The department shall appoint the members of the committee which must consist of qualified physicians, researchers, other experts engaged professionally in cancer prevention and care in South Carolina, and health care consumers. The committee shall advise and make recommendations to the department about the formulation and implementation of a comprehensive cancer prevention and control program through its review of cancer control services throughout the State. The committee shall:

- (1) advise the department on professional issues pertaining to cancer prevention, detection, care and surveillance;
- (2) participate in the evaluation of cancer programs and services offered through the department;
- (3) serve as advocates for the poor and underserved patients through support of the state-aid cancer clinics;
- (4) assist the department in maintaining liaison with the community and other health care providers; and
- (5) advise the department on the administration of available funds for the prevention, detection, care, and surveillance of cancer.

**SECTION 44-35-100.** Suspension of reporting requirements.

The reporting requirements provided for in Section 44-35-30 are suspended if adequate funding is not provided to the Department of Health and Environmental Control

## Accompanying Regulations

### CHAPTER 61. DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL SECTION 45.

South Carolina Central Cancer Registry [SC ADC 61-45]

#### **61-45.** South Carolina Central Cancer Registry [SC ADC 61-45]

##### Table of Contents

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- G. Procedures for Disclosure of Confidential Information.
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##### A. PURPOSE.

This regulation establishes rules implementing Sections 44-35-20 through -40, 1976 S.C. Code of Laws and Supplement, regarding the South Carolina Central Cancer Registry (SCCCR) requirements for reporting cancer cases, data elements to be collected, content and design of forms and reports, and the procedures for disclosure of confidential registry information.

##### B. DEFINITIONS.

1. "South Carolina Central Cancer Registry (SCCCR)" means the population-based cancer data system for the collection, storage, maintenance, analysis, and dissemination of all cancer cases occurring in South Carolina, diagnosed after December 31, 1995, under the administration of the South Carolina Department of Health and Environmental Control (DHEC).
2. "Reportable cases" means all malignant tumors, pathologically or clinically diagnosed, including in situ and invasive carcinomas, sarcomas, melanomas, leukemias, and lymphomas, excluding carcinoma in situ of the cervix, and all basal and squamous cell carcinomas of non-genital skin sites. Malignant tumors of the skin of genital sites as described in the current edition of the International Classification of Diseases for Oncology published by the World Health Organization, are reportable. Cases of reportable cancers with the following ambiguous terms in the final diagnosis shall also be reported: probable, suspect, suspicious, compatible with, consistent with, and most likely.

3. "Health care providers" means all South Carolina health care facilities and licensed practitioners that diagnose or treat patients with cancer. These include, but are not limited to, hospitals, independent pathology laboratories, freestanding surgical and treatment centers, physicians, nurse practitioners, and physician assistants.

4. "Resident of South Carolina" means a person who lives and sleeps most of the time in or considers their usual home to be in South Carolina as defined by the United States Census Bureau.

5. "Regional registry" means a population-based data system for the collection, storage, maintenance, analysis and interpretation of cancer data for a designated geographic region of the State.

6. "Pathologically diagnosed cancer cases" means cases determined by a licensed physician to have cancer present with histologic (tissue) confirmation.

7. "Clinically diagnosed cancer cases" means cases determined by a licensed physician to have cancer present without histologic (tissue) confirmation.

8. "North American Association of Central Cancer Registries (NAACCR)" means the body that establishes standards for central cancer registry operations.

9. "Department" or DHEC means the South Carolina Department of Health and Environmental Control.

10. "DHEC Cancer Control Advisory Committee (CCAC)" means the multidisciplinary committee that advises the Board of DHEC and the staff of the Division of Cancer Prevention and Control on professional issues pertaining to cancer prevention, detection, care, and surveillance. This includes all SCCCR activities.

11. "Surveillance Subcommittee" means the subcommittee of the DHEC Cancer Control Advisory Committee that is comprised of statewide representation of cancer researchers, the South Carolina Medical Association, the South Carolina Hospital Association, and the South Carolina Budget and Control Board Office of Research and Statistics. This subcommittee has the specific responsibility to determine the appropriateness of requests for confidential data release from the SCCCR.

### C. REPORTING OF CANCER CASES.

1. Reportable cancer cases, as defined, which are initially diagnosed after December 31, 1995 shall be reported to DHEC within six months of initial diagnosis.

2. All health care providers that diagnose and/or treat cancer patients in the State are responsible for reporting cancer cases to DHEC, unless those health care providers are already reporting to a regional cancer registry.

3. Responsibility for Reporting:

- a. Hospitals with existing cancer registries shall designate an appropriate person to be responsible for reporting all SCCCR reportable cases to DHEC.
- b. Hospitals without a cancer registry shall designate the Director of Health Information Management or the functional equivalent employee to be responsible for reporting all SCCCR reportable cases to DHEC.
- c. The Director or the functional equivalent of each independent pathology laboratory and private component of a hospital pathology laboratory shall be responsible for reporting the results of examination of tissue specimens and/or hematology examinations to DHEC. Pathologic and hematologic reports indicating the diagnosis of cancer, that have not been previously reported from that laboratory, shall be reported.
- d. Physicians shall report to DHEC all new cancer cases diagnosed in their offices that are not referred to a hospital in the State for treatment.
- e. The Director or functional equivalent of each freestanding surgical or treatment center shall be responsible for reporting all new cancer cases to DHEC.
- f. Every health care provider shall allow representatives of DHEC upon demand to access, obtain, and copy information from all medical, pathological, and other pertinent records and logs related to cancer cases, as necessary for fulfilling the functions of the SCCCR. Adequate space shall be provided as needed to DHEC staff for record review at South Carolina health care facilities.
- g. Regional registries shall abide by the same reporting requirements as for other health care providers in the State.
- h. SCCCR staff shall be responsible for continuously monitoring compliance of reporting requirements from all health care providers.
- i. SCCCR staff shall be responsible for monitoring timeliness, completeness, and quality of data. Statewide and national quality control audits shall be conducted to assess SCCCR data. The SCCCR shall participate in national quality control audits performed by NAACCR that include review of health care provider records.
- j. Every health care provider shall participate in quality control studies developed by the SCCCR in order to assess timeliness, completeness, and quality of data according to NAACCR standards.
- k. SCCCR staff shall provide appropriate training to health care provider staff on data collection principles and practices as needed.

**D. CANCER CASE IDENTIFICATION.** All health care providers shall provide case finding documents to permit identification of cancer cases to be reviewed and

reported. These case finding documents shall include the following: disease and operation indices for cancer cases; pathology and cytology reports; new patient radiation or chemotherapy logs; and other alternative information deemed necessary to identify or verify reportable cancer cases.

#### E. DATA ITEMS TO BE REPORTED.

All health care providers shall provide to DHEC at least the following data items on all reportable cancer cases in accordance with standard definitions as listed in the current edition of the NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary obtained from the NAACCR . The current edition of NAACCR standards can be obtained from the SCCCR office at DHEC:

1. Last name, first name, middle initial
2. Address at initial diagnosis, including city, county, State, and zip code (zip + 4, where available)
3. Race
4. Spanish/Hispanic origin (if applicable)
5. Sex
6. Birth date
7. Social security number
8. Information on the industrial history of the individual with the cancers, to the extent such information is available from the same medical record
9. Information on the occupational history of the individual with the cancers, to the extent such information is available from the same record
10. Date of diagnosis
11. Date of admission
12. Source of information
13. Primary site of the cancer
14. Morphology type, behavior, and grade
15. Sequence number of the cancer
16. Laterality
17. Diagnostic confirmation

18. Stage of disease (pursuant to Summary Staging Guide)

19. Date and type of first course of definitive treatment when available in the medical record

20. Date of death

21. Underlying cause of death

#### F. CONTENT AND DESIGN OF FORMS AND REPORTS.

1. The information to be reported shall be provided on forms supplied by DHEC. The forms must be completed entirely. Supplemental information can be supplied for forms that cannot be completed entirely by submitting copies of pertinent medical information to include, at a minimum, pathology reports, history and physical, discharge summary, and radiographic reports.

2. Case reports from facilities with existing computerized cancer registries shall be submitted on appropriate electronic medium provided their data items are in accordance with national standards utilized by the SCCCR. The data must be submitted according to the NAACCR standard record layout as specified in the current edition of the Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary.

3. Reportable cases from facilities served by the SCCCR field staff shall be collected in a manner determined by DHEC.

4. The SCCCR staff shall document on standard forms the reportability status and record review status of each health care provider that is contacted.

#### G. PROCEDURES FOR DISCLOSURE OF CONFIDENTIAL INFORMATION.

1. In accordance with Section 44-35-40, all data obtained from cancer reports submitted to the SCCCR are confidential. All data collected is confidential pursuant to Section 44-1-110. Information identifying individuals with cancer is exempt from Freedom of Information requests pursuant to Section 30-4-40, "Freedom of Information Act", and may not be made available to the public. Identifying information regarding patients, physicians, or reporting facilities is not available by subpoena, and may only be released pursuant to a court order.

2. Data collected on patients whose legal residential address is outside the State of South Carolina may be shared with other State cancer registries provided a reciprocal data sharing agreement is in place with the respective State Health Departments. The SCCCR will insure that such agreements with other States provide data confidentiality provisions.

3. The DHEC CCAC shall advise and make recommendations to the Department about the issues related to cancer surveillance, including all Central Cancer Registry activities. A subcommittee of the CCAC called the Surveillance Subcommittee shall

have specific responsibility to determine the appropriateness of requests for confidential data release. Membership of this subcommittee shall consist of statewide representation of cancer researchers, the South Carolina Medical Association, the South Carolina Hospital Association, and the South Carolina Budget and Control Board Office of Research and Statistics. Strict criteria set forth in the SCCCR Data Release Protocol written in coordination with the South Carolina Budget and Control Board Office of Research and Statistics Principles and Protocol for Release of Health Data shall be utilized to review each data release request. This Subcommittee also assures the DHEC Institutional Review Board approval when appropriate in order to assure protection of human subjects.

4. Each applicant requesting access to confidential information will follow the procedure outlined in the SCCCR Data Release Protocol, completing the application and providing the required information, documentation, and assurances. The applicant shall provide, at no cost to the SCCCR, a reprint of each publication using Registry information. Any report or published papers must acknowledge DHEC and the SCCCR and data must only be published according to its intended purpose on the application for data release.

5. Requests for non-confidential data as specified in the SCCCR Data Release Protocol will be processed by SCCCR staff, subject to the confidentiality provisions set forth in DHEC regulations.

#### H. SEVERABILITY.

If any provision of these regulations or the application thereof to any facility, individual or circumstance shall be held invalid, such invalidity shall not affect the provisions or application of the regulations which can be given effect, and to this end the provisions of the regulations are declared to be severable.

APPENDIX B

**Procedure for Reporting Cases that are Reportable-to-State-Only  
(but not my hospital):**

A case that is reportable to the state but not to the registry hospital must be submitted to the SCCCR SEPARATE from the Complete cases.

Registry Hospitals (and SCCCR staff) must submit this separate submission via Web Plus (CDC’s secured web portal). Data must be in NAACCR Data Exchange Record Layout for Record Type A, found in NAACCR Standards for Cancer Registries edition that is applicable to the current year of diagnosis, (see [www.naaccr.org](http://www.naaccr.org) for table). Record Type A is a full case abstract record type including text summaries.

Complete as much detail as possible on each case because if there is sufficient documentation to support the diagnosis, the SCCCR can upload that case as an incident case into the SCCCR database without additional follow-back.

Provide the reason the case was not accessioned at the hospital (answering the question “why is it not reportable to your facility?”). Provide either the code or the definition in the text field for Physical Exam (PE).

1 Case diagnosed prior to 1996 (SCCCR reference year)

2 Non-Analytic - including out of state residents, NED / no active disease at present time, history of cancer with no treatment at present time, or subsequent treatment

3 Consult Only - including pathology only (patient not seen at your facility), 2nd opinion for medical oncology or radiation therapy)

4 Blood Disorders prior to 1/1/2001 (i.e. 238.4 -Polycythemia Vera, 238.6, 238.7, 284.9, 285.0, and 288.3; also 205.1-Chronic Neutrophilic, Leukemia (9963/3) – these cases are used to help filter out cases identified by death certificates with these diagnoses listed as cause of death, helps to determine a date of diagnosis

<u>Required data fields when available</u>
Full Name
DOB
SSN
Full Address at DX
Race



Sex
Primary Site
Date of initial diagnosis
Histology
Behavior
Laterality
Physicians
Place of Dx if noted in medical record
Text to support that the case is reportable to the state, why it was not reportable to the hospital, and any information to help the state determine reportability (follow-back to physician on the case) – very important!