West Virginia Cancer Registry Procedure Manual

2019 Facility-Based Registry Edition

WEST VIRGINIA Department of Health & Human Resources

Bureau for Public Health
West Virginia Cancer Registry
350 Capitol Street, Room 125
Charleston, West Virginia 25301

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Chapter 1

INTRODUCTION TO THE WEST VIRGINIA CANCER REGISTRY

The West Virginia Cancer Registry (WVCR) is a statewide, population-based cancer incidence reporting system. The mission of the WVCR is to collect and analyze cancer data to determine incidence rates by anatomic site, sex, race, geographic location, and other factors and monitor trends in cancer incidence and among West Virginia residents. The WVCR tracks cancer in West Virginia in an effort to promote scientific research, public and professional education programs, and planning and implementation of cancer control and prevention activities.

The WVCR was established by legislation (WV Code §16-5-2a; 64 CSR 68) in 1992. In 1991, the WVCR initiated a breast and cervical cancer registry, expanding to an all-site registry with a reference date of January 1, 1993. Benign and borderline intracranial and central nervous system tumors are reportable if diagnosed January 1, 2002 and later. West Virginia regulations require the reporting of all newly-diagnosed cancer cases to the WVCR within six months of diagnosis. All primary malignant and carcinoma in situ tumors are reportable to the WVCR, with the exception of basal cell or squamous cell carcinoma of the skin and carcinoma in situ of the cervix. Hospitals, physicians, dentists, ambulatory care facilities, radiation facilities, independent laboratories, and any other facility that diagnoses, detects, and/or treats cancer patients is required to file reports with the WVCR. Reporting agreements are maintained with neighboring states so that West Virginia residents diagnosed and/or treated in out-of-state facilities are identified.

Information collected by the WVCR includes demographic characteristics of the patient, medical information on each cancer such as primary site, histologic type, cancer stage and cancer-directed treatment information. The vital status of each patient is followed annually until death. Cause of death is incorporated into the data set if the information is available.

The WVCR participates in the National Program of Cancer Registries (NPCR), established by the Centers for Disease Control and Prevention (CDC) in 1992 by the Federal Cancer Registries Amendment Act (Public Law 102-515). NPCR promotes statewide, population-based registries to collect uniform data elements in a standardized format. The WVCR is also a member of the North American Association of Cancer Registries (NAACCR), which is a professional organization that develops and promotes uniform data standards for cancer registration, provides education and training, certifies population-based registries, and publishes data from central cancer registries.

CONFIDENTIALITY

All WVCR employees sign a confidentiality pledge that meets the requirements of applicable state laws as well as the requirements of the Health Insurance Portability and Accountability Act (HIPAA). West Virginia code protects the confidentiality of both patient and health care provider, and stipulates that "no liability of any kind or character for damages or other relief shall arise or be enforced against any reporting source by reason of having provided the information or material to the cancer and tumor registry." Reporting of information about cases of cancer in accordance with the WVCR authorizing statute and regulations is permitted by HIPAA, which contains a specific provision authorizing covered entities to disclose protected health information as required by law. Please see Appendix A for additional information regarding cancer reporting and HIPAA, and Appendix B for WV Code and Rule (§16-5-2a and 64CSR68).

RELEASE OF IDENTIFIED INFORMATION

West Virginia code permits release of identified data under the following circumstances:

1. Data provided by a facility or reporter may be provided back to that facility or reporter as a failsafe in the event of catastrophic data loss. However, ONLY data provided by the facility or reporter may be provided. Additional information provided by other sources may NOT be disclosed.

2. When a lawful reciprocal data sharing agreement exists, WVCR may provide identified data about another state or territory's residents or tribal entity's members diagnosed and/or treated in West Virginia back to the state/territory/tribal entity, which, in turn, is to provide WVCR with identified data on West Virginia residents.

3. A researcher can access identifiable data for patients in his/her study from whom a release of information is signed and provided to the WVCR after a research application is approved.

Chapter 2

GENERAL REQUIREMENTS FOR REPORTING TO WVCR

Rule 64CSR68, Section 3.11. requires the reporting of "(a)ny case of cancer diagnosed after December 31, 1992, where the primary tumor is determined to be malignant or carcinoma in situ, with the exception of basal cell or squamous cell carcinomas of the skin and carcinoma in situ of the cervix," and West Virginia Code §16-5A-2a(b) mandates the inclusion of "nonmalignant intracranial and central nervous system tumors" as well. Both the Rule and Code are provided in their entirety in Appendix B.

WHAT TO REPORT

- All cases of cancer diagnosed on or after **January 1, 1993**.
- Intraepithelial neoplasia Grade III (vulvar intraepithelial neoplasia (VIN) Grade III, vaginal intraepithelial neoplasia (VAIN) Grade III, anal intraepithelial neoplasia (AIN) Grade III).
- Benign and borderline primary intracranial and central nervous system (CNS) tumors diagnosed on or after **January 1, 2002** with a behavior code of /0 or /1 in ICD-O-3 for the following sites: brain (C71.0-C71.9); meninges (C70.0-C70.9); spinal cord, cranial nerves, and other parts of the central nervous system (C72.0-C72.9); and pituitary and pineal glands (C75.1-C75.3)**.**
- All cancer patients diagnosed or treated in the inpatient or outpatient department, emergency room, clinic, ambulatory care center, radiation therapy facility, oncology facility, laboratory, or any other health care facility must be reported including patients receiving transient care.
- Cases presented only at a facility's tumor board or cancer conference.
- Cases diagnosed at autopsy and patients' dead on arrival with a cancer diagnosis.
- Patients diagnosed elsewhere and admitted for additional work-up and/or treatment, cancer-directed or non-cancer directed.
- Patients with a clinical diagnosis of cancer which was based on clinical judgement.
- Patients with a history of cancer.
- Consult-only cases.

PLEASE NOTE THE FOLLOWING

- Non-analytic cases of Class 30-99 **are** required to be reported to the WVCR.
- Cases seen in free-standing diagnostic or treatment facilities that are owned and/or operated by a facility or otherwise a part of that facility are to be reported by that facility.
- Private outpatient specimens are reportable. Generally, these specimens are submitted from a physician's office to be read by a hospital pathologist and the patient is not registered as an inpatient or outpatient at the facility.
- The ICD-O-3 coding scheme must be used for site and histology for cases diagnosed on or after January 1, 2001. The ICD-O-2 coding scheme must be used for cases diagnosed prior to January 1, 2001.

NON-REPORTABLE NEOPLASMS

- Cancer cases diagnosed prior to January 1, 1993.
- Carcinoma in situ of the cervix (any histology type /2) and cervical intraepithelial neoplasia (CIN) III (C53.0-C53.9).
- Benign and borderline neoplasms of the ovary.
- Prostatic intraepithelial neoplasia (PIN) III (C61.9).
- Basal and squamous cell carcinomas of the skin (C44.0-C44.9) except as follows:
  Epithelial carcinomas, papillary and squamous cell carcinomas, and basal cell carcinomas of the skin of the following mucoepidermoid sites **are** reportable regardless of stage: lip (C00.0-C00.9), anus (C21.0), vulva (C51.0-C51.9), vagina (C52.9), penis (C60.0-C60.9), and scrotum (C63.2).
- Primary tumors with a behavior code of "0" (benign) and "1" (borderline) are *not* reportable, *except* benign primary brain and CNS tumors as specified in reportable section.

COMPUTERIZED EDITS

All cancer registry software offers the possibility of running computerized edits. The WVCR requires that all registrars run edits on their cases before submitting them. This will greatly improve the quality of data in hospital registries and the quality of data provided to the WVCR.

WHEN TO REPORT TO THE WVCR

West Virginia Legislative Rule, Cancer Registry, 64CSR68, Section 4.3a, ***requires that cases be reported to the WVCR within six (6) months of diagnosis.*** Failure to report in compliance with 64CSR68 subjects' persons to "criminal penalties prescribed in West Virginia Code §16-1-18," including fines. The WVCR will provide regular feedback to reporters regarding the timeliness of their reports.

HOW TO REPORT TO THE WVCR

In accordance with NPCR requirements, all abstracts from health care facilities must be submitted electronically in the latest NAACCR format.

- For abstract reports: The NAACCR record layout version specified *in* ***year-appropriate*** *Standards for Cancer Registries: Data Standards and Data Dictionary.*
- For pathology reports: *NAACCR Standards for Cancer Registries: Pathology Laboratory Electronic Reporting.*

The WVCR requires electronic reporting via an internet-based secure file transfer protocol (SFTP) site. If under special circumstances reporters must mail data, the data must be encrypted and the mailing method should allow for tracking. All facilities should report monthly by the 10th of each month. Access to the secure submission site can be obtained by contacting the WVCR Data Manager.

REQUIRED DATA ELEMENTS

The WVCR bases decisions about required data elements on what is required by West Virginia Code (Appendix B) and what is required by the NPCR and NAACCR. The most recent version of the NAACCR Required Status Table (Version 18) is available at http://datadictionary.naaccr.org/ If this table notes that a data item is required by NPCR, it is therefore required by the WVCR.

FOLLOW-UP INFORMATION

Additional follow-up information is not required by the WVCR on any case.

Chapter 3

CASE ASCERTAINMENT

CASEFINDING

Casefinding is the system used to identify patients with reportable diagnoses, and involves thorough, systematic monitoring of records maintained by various departments throughout a facility. Casefinding sources include, but are not limited to:

- Medical record disease index
- Admission and discharge documents
- Pathology and cytology reports
- Surgery schedules/logs
- Autopsy reports
- Medical imaging
- Outpatient medical records/logs, including radiation, chemotherapy, and nuclear medicine

SCREENING LISTS OF ICD-10-CM CODES FOR CASEFINDING

Certain ICD-10-CM codes are used by medical records departments for discharge diagnoses to identify cases of neoplasms that are reportable. Casefinding procedures should include review of medical records with ICD-10-CM codes found in Appendix C.

AMBIGUOUS TERMINOLOGY

Ambiguous terminology may originate in any source document, such as a pathology report, radiology report or clinical report. The terms listed below are reportable when they are used with a term such as cancer, carcinoma, sarcoma, etc. Do not substitute synonyms such as "supposed" for presumed or "equal" for comparable. Do not substitute "likely" for "most likely." Note: cytology cases must be confirmed with a definitive diagnosis. Do not report cytology cases with ambiguous terminology.

Ambiguous terms that constitute a diagnosis

Apparent(ly)	Favors	Probable
Appears to	Malignant appearing	Suspect
Comparable with	Most likely	Suspicious
Compatible with	Presumed	Typical of
Consistent with		

Ambiguous terms that are NOT reportable

Cannot be ruled out	Potentially malignant	Suggests
Equivocal	Questionable	Worrisome
Possible	Rule out	

See the Surveillance, Epidemiology, and End Results (SEER) Program Coding and Staging Manual 2016 for detailed information on how to use ambiguous terminology for case ascertainment. http://seer.cancer.gov/manuals/2016/SPCSM_2016_maindoc.pdf

CHANGING INFORMATION ON THE ABSTRACT

Data are gathered from multiple sources using the most recent and complete information available. Over time, the patient's records may contain new information such as tests, scans and consults. Change the primary site, laterality, histology and stage as the information becomes more complete. There is no time limit for making revisions that give better information about original diagnosis or stage. Information originally collected on an abstract should be changed or modified under the following circumstances:

- To correct coding or abstracting errors.
- When clarifications or rule changes retroactively affect data item codes.
- When better information is available later.
- When the date of diagnosis is confirmed in retrospect to be earlier than the original date abstracted.

Chapter 4

INTRODUCTION TO ABSTRACTING

ABSTRACTING RESOURCES

This edition of the WVCR Facility-Based Reporting Manual does not contain the manuals/resources listed below; however, use of each is required when abstracting and submitting to the WVCR. These resources are available for download from the web addresses provided.

1. Facility Oncology Registry Data Standards (FORDS)
   http://www.facs.org/cancer/coc/fords/fords-manual-2016.pdf
   This manual instructs on the types of tumors that require data collection, defines how to accurately complete and code most fields of an abstract, and identifies site-specific surgery codes for cases diagnosed prior to January 1, 2018.

2. Standards for Oncology Registry Entry (STORE)
   https://facs.org/quality-programs/cancer/ncdb/registrymanuals.cocmanuals
   This manual instructs on the types of tumors that require data collection, defines how to accurately complete and code most fields of an abstract, and identifies site-specific surgery codes for cases diagnosed January 1, 2018 and forward.

3. Collaborative Stage Data Collection System (CS), Version 02.05, October 2013
   https://cancerstaging.org/cstage
   This manual is used to derive a stage after completing multiple questions about the tumor extension and how that information was identified. Collaborative Stage Data Collection System, Version 02.05 is required for use with cancers diagnosed on and after January 1, 2004 through December 31, 2015.

4. The SEER Summary Stage Manuals
   http://seer.cancer.gov/tools/ssm/
   The SEER Summary Stage Manual 2018 is to be uses with cases diagnosed January 1, 2018 and forward, SEER Summary Staging Manual 2000 is to be used for cases diagnosed between January 1, 2001 and December 31, 2017, SEER Summary Staging Guide 1977 is to be used for cases diagnosed prior to January 1, 2001.

5. 2007 Multiple Primary and Histology Rules (MP/H)
   http://seer.cancer.gov/tools/mphrules/
   This manual is used to determine the number of primaries and histology codes for each case diagnosed January 1, 2007 through December 31, 2017.

6. Solid Tumor Rules (replaced 2007 MP/H Rules)
   http://seer.cancer.gov/tools/solidtumor/
   This manual is used to determine the number of primaries and histology codes for each case diagnosed January 1, 2018 and forward.

7. Hematopoietic & Lymphoid Neoplasm Coding Manual and Hematopoietic Database
   http://seer.cancer.gov/seertools/hemelymph/
   This manual provides reportability instructions and rules for determining the number of primaries, the primary site and histology, and the cell lineage or phenotype. The database contains abstracting and coding information for all hematopoietic and lymphoid neoplasm (9590/3 – 9992/3) and is a tool to assist in screening for reportable cases and determining reportability requirements.

8. SEER*Rx – Interactive Antineoplastic Drugs Database
   http://seer.cancer.gov/tools/seerrx/
   This database was developed as a one-step lookup for coding oncology drug and regiment treatment categories in cancer registries. Information in this database is effective for cancer diagnoses made on January 1, 2005 and after.

9. American Joint Committee on Cancer (AJCC) Cancer Staging Manual, 7th Edition
   Available for purchase from http://cancerstaging.org
   This staging system is based on the extent of the tumor (T), the extent of spread to the lymph nodes (N), and the presence of metastasis (M). Transition from CS to TNM will occur during 2014-2015, with TNM being fully implemented for cases diagnosed January 1, 2010 through December 31, 2017. AJCC Cancer Staging Manual 8th Edition (TNM) is for cases diagnosed January 1, 2018 and forward.

10. Site-Specific Data Item (SSDI) Manual
    http://apps.naaccr.org/ssdi/list/
    The SSDI Manual is the primary resource for documentation and coding instructions for site-specific data items and schema discriminator 1-3 for cases diagnosed January 1, 2018 and forward. Most of the SSDI Manual data items were previously collected in the Collaborative Stage v2(CSv2) Manual Part I, Section II for Site specific Factors (SSF).

11. Grade Coding Instructions and Tables
    https://apps.naaccr.org/ssdi/list/
    The Grade Coding Instructions and Tables (Grade Manual) is the primary resource for documentation and coding instructions for Grade for cases diagnosed January 1, 2018 and forward. The Grade manual reflects several important changes in collection of grade data items including the introduction of Clinical, Pathological and Post Therapy Grade data items.

Please stay abreast of revisions to manuals by periodic check of websites specific to provider of manual.

TEXT DOCUMENTATION IS REQUIRED

Rule 64CSR68, Section 4.2.c. requires that hospitals provide "(s)ufficient narrative to determine the accuracy of coding and information." Text is used for quality control purposes to justify codes for various data items. Text is also used to identify errors, to determine multiple primaries and to resolve discrepancies in data submitted on the same patient by multiple facilities. Text documentation should include the following items and any other items needing clarification:

- Record text to identify place of diagnosis if other than at the reporting facility.
- Record text to identify usual occupation and usual industry.
- Record text to validate primary site, laterality, histology, grade, tumor size, stage, and treatment codes.
- Record text to clarify modifications or dates on the abstract.
- Record text to describe diagnostic procedures, including physical exam, pathology, operative notes, imaging/scans, lab tests, scopes, and any other diagnostic procedure used to identify reportable conditions.
- Record text to identify other primary tumors.
- Record text to note when limited information is available in the medical record about a case.

Upon completion of an abstract, it is good practice to perform visual editing:

- Check all dates.
- Check demographic information.
- Verify that the text supports the items listed above, as well as any other items needing clarification.

PATIENT INFORMATION

Unique Patient Identifier Codes

Accession Numbers and Sequence Numbers uniquely identify the patient and the tumor. Each cancer patient in a registry is assigned a unique accession number (abstract number), and each primary diagnosed for that patient is assigned a sequence number. The accession number never changes. The sequence number indicates the sequence of all reportable tumors over the lifetime of a patient. Only tumors that would have been reportable at the time of diagnosis are required to be counted when assigning sequence numbers. Tumors are sequenced as follows:

Malignant Tumors:

- 00 = One primary in a patient's lifetime
- 01 = First of two or more primaries
- 02 = Second of two or more primaries
- Additional primaries numbered consecutively

Non-malignant Tumors:

- 60 = One non-malignant tumor
- 61 = First of two or more non-malignant tumors
- 62 = Second of two or more non-malignant tumors
- Additional non-malignant tumors numbered consecutively

Name

Record patient's last name, first name, and middle name or initial in the spaces designated for that purpose. Do not use spaces or punctuation. Hyphenated names are allowed (e.g. JONES-SMITH).

Name – Prefix/Suffix

Abbreviated titles may be recorded. Do not use periods or spaces (e.g., MS, MD). Titles should not be recorded in the same space as first or last name.

Address at Diagnosis

Record the patient's residence when the tumor was first diagnosed, which may differ from the patient's current address. The address should be the residence, not the mailing address. In general, use the address of the location where a person lives and sleeps **most** of the time, or the place the person says is his or her usual home.

Post office box is **not** a reliable source to identify the residence at diagnosis. Post office box addresses do not provide accurate geographic information for analyzing cancer incidence. Use the post office box address only if no street or rural address is available.

Codes for unknown or partially known addresses are as follows:

DATA ELEMENT	CONDITION	CODE
Address	Address not known	Unknown
City	City not known	Unknown
Zip	Zip not known	99999
State	Resident of a country other than the U.S. or Canada and the country is known	XX
State	Resident of a country other than the U.S. or Canada and the country is unknown	YY
State	Resident of U.S., not otherwise specified (NOS); resident of Canada, NOS; residence unknown	ZZ

Please refer to the United States Postal Service website for lists of official abbreviations for states, street suffixes and secondary units https://pe.usps.com/text/pub28/28c2_toc.htm?q=state+abbreviations+with+stree+suffixes+and+secondary+units&t=H&s=R&p=1&c=Pub28 , and zip codes (https://www.usps.com).

County

West Virginia residents should be assigned the code for county of residence issued by the Federal Information Processing Standards (FIPS) publication, *Counties and Equivalent Entitles of the United States, Its Possessions, and Associated Areas*. This publication can be accessed at https://www.census.gov/2010census/partners/pdf/FIPS_StateCounty_Code.pdf. Outt-of-state residents should be coded as 998 and persons who are West Virginia residents but the county is unknown should be coded 999.

Current Address

This field should be completed only if the current address is different than the address at diagnosis.

Social Security Number (SSN)

Record the patient's SSN without dashes. SSNs ending with B or D should **not** be reported as they may indicate a patient receiving care under a spouse's SSN. If the SSN is unknown, enter as 999999999. Accurate recording of the SSN is critical to record de-duplication and has become increasingly important as central cancer registries perform data linkages with the Indian Health Service and the National Death Index.

Race

Accurate reporting of Race 1-5 is vital to understanding the burden of cancer in West Virginia, describing race-associated differences in cancer incidence and tracking temporal changes in race-associated disparities in stage at diagnosis and treatment.

CODE	DEFINITION	CODE	DEFINITION
01	White	20	Micronesian, NOS
02	Black	21	Chamorro/Chamoru
03	American Indian, Aleutian, Eskimo (includes South and Central American Indians)	22	Guamanian, NOS
04	Chinese	25	Polynesian, NOS
05	Japanese	26	Tahitian
06	Filipino	27	Samoan
07	Hawaiian	28	Tongan
08	Korean	30	Melanesian, NOS
10	Vietnamese	31	Fiji Islander
11	Laotian	32	New Guinean
12	Hmong	88	No further race
13	Kampuchean (Cambodian)	96	Other Asian-Asian/Oriental, NOS
14	Thai	97	Pacific Islander, NOS
15	Asian Indian or Pakistani, NOS (formerly code 09)	98	Other
16	Asian Indian	99	Unknown
17	Pakistani		

Note: If diagnosed prior to January 1, 2000, Race 2-5 must be blank. If only one race is reported for the person, use code 88 for remaining race fields (Race 2-5). If Race 1 is coded as 99 (Unknown), Race 2-5 must also be 99.

Mexican, Puerto Rican, or Cuban origins are coded as White.

If a person is multiracial and one of the races is White, code the other race(s) first, followed by White, and any remaining fields with 88.

Usual Occupation

Record the patient's usual occupation **regardless of whether the patient is currently employed or retired**. Usual occupation refers to the type of job the individual performed during most of his/her working life. If the patient was a housewife/house husband and did not work outside the home for most of her/his adult life, record housewife or house husband. If the patient is a student and has never been employed, record never worked. If no information is available, record unknown. Do not record retired.

Usual Industry

Record the type of activity carried on by the business/industry where the patient was employed for the longest time before diagnosis of this tumor (e.g., coal mining, food preparation, school). If type of industry is not known, record the name of the company. If no information is available, code as unknown. Do not record retired.

Spanish/Hispanic Origin

Spanish/Hispanic origin is NOT dependent on race. A person of Spanish or Hispanic origin may be of any race. The following codes are to be used for Spanish/Hispanic Origin:

CODE	DESCRIPTION	EFFECTIVE DATE
0	Non-Spanish/Non-Hispanic (includes Portuguese, Brazilians and Filipinos, which are not Spanish or Hispanic)	1/1/93
1	Mexican (includes Chicano)	1/1/93
2	Puerto Rican	1/1/93
3	Cuban	1/1/93
4	South or Central American (except Brazil)	1/1/93
5	Other specified Spanish/Hispanic origin (includes European, excludes Dominican Republic)	1/1/93
6	Spanish, NOS; Hispanic, NOS; Latino, NOS There is evidence, other than surname or maiden name, that the person is Hispanic but s/he cannot be assigned to any of the categories 1-5	1/1/93
7	Spanish surname only The only evidence of the person's Hispanic origin is the surname or maiden name and there is no contrary evidence that the person is not Hispanic	1/1/94
8	Dominican Republic	1/1/05
9	Unknown whether Spanish/Hispanic	1/1/93

Use all information to determine Spanish/Hispanic origin including:

- The ethnicity stated in the medical record
- Hispanic origin stated on the death certificate
- Birthplace
- Information about life history and/or language spoken found in the abstracting process
- Last name or maiden name found on a list of Hispanic/Spanish surnames

CANCER INFORMATION

When collecting information about the cancer, begin by reading the patient history and physical examination to find information associated with the illness, details of any workup that has already been performed, and past history of other malignancies. Review all imaging reports, scopes, surgeries, pathology and cytology reports, and the discharge summary to identify the primary site and the extent of disease for staging. Some cases will be a clinical diagnosis made by the physicians and may not be confirmed by biopsy at your facility.

Primary Site

Use the ICD-O-3 manual to code the primary site for cases diagnosed on or after January 1, 2001, or the ICD-O-2 manual for cases diagnosed prior to January 1, 2001. Follow all general rules as well as Site-Specific Data Item (SSDI) Manual rules to determine the number of primaries and corresponding abstracts to be completed. Use all information available in the medical record to determine the specific site.

The following guidelines should be followed for consistent analysis of primary sites for particular histologies:

Hematopoietic and Lymphoid Cancers – Beginning with cases diagnosed January 1, 2010, the Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual http://seer.cancer.gov/seertools/hemelymph/ is to be used for coding primary site, histology, and grade of hematopoietic and lymphoid (M9590-9992) and to determine whether multiple conditions represent one or more cases to be abstracted. Appendix A in the Hematopoietic Manual contains a table for use with cases diagnosed prior to January 1, 2010 for determining unique or same hematopoietic cases.

Kaposi Sarcoma (KS) – Code KS to the site in which it arises. Code to Skin, NOS (C44.9), if KS arises simultaneously in the skin and another site or the primary site is not identified.

Melanoma – Code to Skin, NOS (C44.9), if a patient is diagnosed with metastatic melanoma and the primary site is not identified.

Histology/Behavior/Grade

Use the correct ICD-O manual to assign the codes. All pathology and cytology reports for the case should be reviewed to determine the most accurate histology. Refer to and follow all general as well as site-specific rules in Site-Specific Data (SSDI) Item Manual to determine correct histology. Review in situ reports carefully to determine if invasion or microinvasion is noted. If even a **tiny focus** of invasion is documented on the pathology report the case is no longer considered in situ but invasive.

NOTE: Instructions for coding grade can be found in the Grade Coding Instruction and Tables Manual at http://apps.naaccr.org/ssdi/list/ and are to be implemented for cases diagnosed **January 1, 2018 and forward.**

Diagnostic Confirmation

Record the best method of diagnostic confirmation of the cancer being reported at any time in the patient's history. The rules for coding differ between solid tumors and hematopoietic and lymphoid neoplasms. Codes are in priority order; code 1 has the highest priority. Always code the procedure with the lower numeric value (highest priority) when cancer is confirmed with multiple diagnostic methods.

Codes for Solid Tumors (all tumors *except* M9590-9992)

Code	Label	Definition
1	Positive histology	Histologic confirmation (tissue microscopically examined)
2	Positive cytology	Cytologic confirmation (no tissue microscopically examined; fluid cells microscopically examined)
4	Positive microscopic confirmation, method not specified	Microscopic confirmation is all that is known. It is unknown if the cells were from histology or cytology.
5	Positive laboratory test/marker	A clinical diagnosis of cancer is based on laboratory tests/marker studies which are clinically diagnostic for cancer.
6	Direct visualization without microscopic confirmation	Tumor was visualized during a surgical or endoscopic procedure only with no tissue resected for microscopic examination.
7	Radiography and other imaging techniques without microscopic confirmation	The malignancy was reported by the physician from an imaging technique report only.
8	Clinical diagnosis only (other than 5, 6 or 7)	The malignancy was reported by the physician in the medical record.
9	Unknown whether or not microscopically confirmed	A statement of malignancy was reported in the medical record, but there is no statement of how the cancer was diagnosed.

Codes for Hematopoietic and Lymphoid Neoplasms

Code	Label	Definition
1	Positive histology	Histologic confirmation (tissue microscopically examined)
2	Positive cytology	Cytologic confirmation (no tissue microscopically examined; fluid cells microscopically examined)
3	Positive histology PLUS • Positive immunophenotyping AND/OR • Positive genetic studies	Histology is positive for cancer, and there are also positive immunophenotyping and/or genetic test results. For example, bone marrow examination is positive for acute myeloid leukemia (9861/3). Genetic testing shows AML with inv(16)(p13.1q22) (9871/3).
4	Positive microscopic confirmation, method not specified	Microscopic confirmation is all that is known. It is unknown if the cells were from histology or cytology.
5	Positive laboratory test/marker	A clinical diagnosis of cancer is based on laboratory tests/marker studies which are clinically diagnostic for cancer.
6	Direct visualization without microscopic confirmation	Tumor was visualized during a surgical or endoscopic procedure only with no tissue resected for microscopic examination.
7	Radiography and other imaging techniques without microscopic confirmation	The malignancy was reported by the physician from an imaging technique report only.
8	Clinical diagnosis only (other than 5, 6 or 7)	The malignancy was reported by the physician in the medical record.
9	Unknown whether or not microscopically confirmed	A statement of malignancy was reported in the medical record, but there is no statement of how the cancer was diagnosed.

Date of Diagnosis

Use the first date of diagnosis whether clinically or histologically confirmed. If the physician states that in retrospect the patient had cancer at an earlier date, use the earlier date as the date of diagnosis. If the year of diagnosis cannot be identified, it must be approximated. In that instance, the month and day are unknown.

Treatment

First course of therapy is all treatment planned at initial diagnosis, which may take up to a year or more to complete. Treatment means cancer-directed therapy that modifies, controls, removes or destroys primary or metastatic cancer tissue. This includes all methods of treatment recorded in the treatment plan and administered to the patient before disease progression or recurrence. "Active surveillance/watchful waiting" is a form of planned treatment for some patients, and is coded in the RX Summary-Treatment Status item. "No therapy" is a treatment option that occurs if the patient refuses treatment, the family or guardian refuses treatment, the patient dies before treatment starts or the physician recommends no treatment be given. If the patient refuses all treatment, code as "patient refused" (code 7 or 87) for all treatment modalities. If there is progression of disease during first course treatment and the treatment plan is changed, it is no longer considered first course treatment. If the patient becomes disease free and then has a recurrence the treatment is always considered subsequent therapy.

Staging Requirements

CDC NPCR: Effective with cases diagnosed January 1, 2018 and forward, CDC requires directly assigned SEER Summary Stage 2018 and Site-Specific Data (SSDI) Items. See (Appendix E) for SSDI that are required by CDC/NPCR for 2018 cases. SEER Summary Stage 2000 and AJCC TNM 7th Edition Clinical and Pathologic Stage for cases diagnosed January 1, 2016 through December 31, 2017 is required in lieu of CSv2, Site Specific (SSF) Factors are also required for these years of diagnoses. The Collaborative Stage Data Collection System Version 02.05 and Site-Specific Factors (SSF) will continue to be used for cases diagnosed 2004-2015.

AJCC-TNM Stage Requirements

Please refer to the AJCC TNM Staging Manual and Coding Instructions for codes and instructions. Directly coded clinical and pathologic AJCC-TNM 7th Edition stage is required for all cases diagnosed on 1/1/2016 and 12/31/2017. Additional information and training for registrars can be found on the AJCC Website: https://cancerstaging.org/CSE/Registrar/Pages/default.aspx

SEER Summary Stage Requirements

Please refer to the SEER Summary Staging Manual for Coding Instructions. Record the SEER Summary Stage at diagnosis in the appropriate Summary Stage field according to SEER Summary Stage 2018 (SS2018), SEER Summary Stage 2000 (SS2000) or SEER Summary 1977 (SS77) based on date of diagnosis. Manuals are available online at http://seer.cancer.gov/tools/ssm/.

Collaborative Stage Requirements

Please refer to the Collaborative Staging Manual and Coding Instructions for codes and instructions. Schemas for the collaborative staging system apply to cases diagnosed January 1, 2004 through December 31, 2015. For cases diagnosed prior to January 1, 2004, please refer to the coding system applicable to the time of diagnosis. Please note that there are distinct versions of the Collaborative Staging System based on year of diagnosis. Manuals are available online at www.cancerstaging.org/csstage/

Coding and Staging Manuals
Effective Dates

Year of Diagnosis	Stage System/Manual
Jan. 1, 1993 - Dec. 31, 2000	SEER Summary Stage Guide 1977 (SS77)
Jan. 1, 2001 - Dec. 31, 2017	SEER Summary Stage Manual 2000 (SS2000)
Jan. 1, 2018 and forward	SEER Summary Stage Manual 2018 (SS2018)
Jan. 1, 2004 - Dec. 31, 2015	Collaborative Stage Data Collection System Coding Instruction, Version 02.05
Jan. 1, 2015 - Dec. 31, 2017	AJCC-TNM Cancer Staging Manual, Seventh Edition

ICD-O Coding Manual Requirements

This manual is used to code primary site (topography) and the cell type (morphology) of the cancer/tumor condition being reported to WVCR, using ICD-O-3 or ICD-O-2 (*International Classification of Diseases for Oncology, Third or Second Edition* published by the World Health Organization).

Coding Primary Site and Histology Manuals
Effective Dates

Year of Diagnosis	Coding Manual
Jan. 1, 1995 – Dec. 31, 2000	International Classification of Diseases for Oncology, 2nd Edition (ICD-O-2)
Jan. 1, 2001 and forward	International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3)

2018 Solid Tumor Multiple Primary and Histology Coding Rules Requirements

Please refer to the Determining Multiple primaries for Solid Tumors: Apply the general instructions and site-specific instructions for determining multiple primaries in the 2018 Solid Tumor MP/H Coding Rules Manual at https://seer.cancer.gov/tools/solidtumor/

Determining Multiple primaries for Hematopoietic and Lymphoid Neoplasms: Apply the Multiple Primary Rules in the Hematopoietic and Lymphoid Neoplasm Coding Manual and Database at https://seer.cancer.gov/seertools/hemelymph/

Multiple Primary and Histology Coding Rules Manual
Effective Dates

Year of Diagnosis	Coding Manual
Jan. 1, 2007 - forward	Multiple Primary and Histology Coding Rules Manual 2007 (MP/H)
Jan. 1, 2010 - forward	Hematopoietic and Lymphoid Neoplasm Coding Manual and Database

Ambiguous Terms Describing Tumor Spread

If the wording in the patient record is ambiguous with respect to tumor spread, use the following guidelines:

Terms that Constitute Tumor Involvement or Extension		**Terms that *Do Not* Constitute Tumor Involvement or Extension**
Adherent	Into	Approaching
Apparent	Onto	Equivocal
Compatible with	Out onto	Possible
Consistent with	Probable	Questionable
Encroaching upon	Suspect	Suggests
Fixation, fixed	Suspicious	Very close to
Induration	To	

Chapter 5

QUALITY CONTROL

FACILITY ACTIVITIES

Facilities are responsible for the following quality control activities:

- Maintaining complete and up-to-date coding manuals and a library of references sufficient to support abstracting activities.
- Providing sufficient text to substantiate coding decisions.
- Running and resolving computer edits prior to data submission.
- Maintaining the following standards, based on NAACCR certification standards and NPCR data quality standards:

ISSUE	STANDARD
Completeness	>98%
Timeliness	>95% of cases diagnosed at facility reported within 6 months of diagnosis
Non-specific histologies	<1.0%
Unknown or missing grade	<10.0% of cases diagnosed at your facility
Unknown diagnostic confirmation	<0.1% of cases diagnosed at your facility
Unknown or non-specific primary	<1.0% of cases diagnosed at your facility
Unknown or missing laterality for cases that should have laterality	<1.0% of cases that should have laterality
Laterality assigned to cases that should NOT have laterality	<0.01%
Unknown or missing stage	<2.0%
Unknown or missing sex	<0.01%
Unknown or missing age at diagnosis	<0.1%
Unknown or missing county at diagnosis	<0.1%
Unknown or missing race	<1.0%
Unknown or missing ethnicity	<1.0%
Unknown or missing SSN	<2.5%
Missing primary payer at diagnosis	<1.0%

WVCR ACTIVITIES

WVCR is responsible for the following quality control activities:

- Regular conduct of casefinding and reabstracting audits in accordance with current NPCR protocol. Hospitals will be audited at least once every three to five years or more frequently to address quality and/or completeness problems.
- Running and resolution of computerized edits.
- Visual review of at least 10% of abstracts.
- Regular feedback to hospitals concerning timeliness, completeness and other aspects of data quality.
- Provision of centralized training as resources permit.

ACKNOWLEDGEMENTS

The following sources were used in preparation of this manual:

2015 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual
Johnson CH, Adamo M, Ruhl J, Dickie L (eds.), 2015 *Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual*. National Cancer Institute, Bethesda, MD 20850-9765.

Collaborative Staging Manual and Coding Instructions, version 02.05
Collaborative Stage Work Group of the American Joint Committee on Cancer. *Collaborative Stage Data Collection System User Documentation and Coding Instructions, version 02.05* Published by
American Joint Committee on Cancer (Chicago, IL).

Facility Oncology Registry Data Standards (FORDS) Manual 2016
Facility Oncology Registry Data Standards (FORDS): Revised for 2016, Commission on Cancer of the American College of Surgeons; Chicago, IL, 2002.

Multiple Primary and Histology Coding Rules
Johnson CH, Peace S, Adamo P, Fritz A, Percy-Laurry A, Edwards BK. *The 2007 Multiple Primary and Histology Coding Rules.* National Cancer Institute, Surveillance, Epidemiology and End Results Program. Bethesda, MD, 2007.

SEER Program Coding and Staging Manual 2016
Adamo MB, Johnson CH, Ruhl JL, Dickie, LA, (eds.) *2016 SEER Program Coding and Staging Manual.* National Cancer Institute, NIH Publication number 10-5581, Bethesda, MD.

SEER Training Materials

Wyoming Cancer Surveillance Program, Cancer Reporting Manual 2015

APPENDIX A:

United States Department of Health and Human Services Findings on the Permissibility of Reporting to Public Health Authorities under HIPAA

and

North American Association of Central Cancer Registries Legal Opinion of Permissibility of Reporting to Central Cancer Registries

DISCLOSURES FOR PUBLIC HEALTH ACTIVITIES

[*45 CFR 164.512(b)*]

Background

The HIPAA Privacy Rule recognizes the legitimate need for public health authorities and others responsible for ensuring public health and safety to have access to protected health information to carry out their public health mission. The Rule also recognizes that public health reports made by covered entities are an important means of identifying threats to the health and safety of the public at large, as well as individuals. Accordingly, the Rule permits covered entities to disclose protected health information without authorization for specified public health purposes.

How the Rule Works

General Public Health Activities. The Privacy Rule permits covered entities to disclose protected health information, without authorization, to public health authorities who are legally authorized to receive such reports for the purpose of preventing or controlling disease, injury, or disability. This would include, for example, the reporting of a disease or injury; reporting vital events, such as births or deaths; and conducting public health surveillance, investigations, or interventions. See 45 CFR 164.512(b)(1)(i). Also, covered entities may, at the direction of a public health authority, disclose protected health information to a foreign government agency that is acting in collaboration with a public health authority. See 45 CFR 164.512(b)(1)(i). Covered entities who are also a public health authority may use, as well as disclose, protected health information for these public health purposes. See 45 CFR 164.512(b)(2).

A "public health authority" is an agency or authority of the United States government, a State, a territory, a political subdivision of a State or territory, or Indian tribe that is responsible for public health matters as part of its official mandate, as well as a person or entity acting under a grant of authority from, or under a contract with, a public health agency. See 45 CFR 164.501. Examples of a public health authority include State and local health departments, the Food and Drug Administration (FDA), the Centers for Disease Control and Prevention, and the Occupational Safety and Health Administration (OSHA).

Generally, covered entities are required reasonably to limit the protected health information disclosed for public health purposes to the minimum amount necessary to accomplish the public health purpose. However, covered entities are not required to make a minimum necessary determination for public health disclosures that are made pursuant to an individual's authorization, or for disclosures that are required by other law. See 45 CFR 164.502(b). For disclosures to a public health authority, covered entities may reasonably rely on a minimum necessary determination made by the public health authority in requesting the protected health information. See 45 CFR 164.514(d)(3)(iii)(A). For routine and recurring public health disclosures, covered entities may develop standard protocols, as part of their minimum necessary policies and procedures, that address the types and amount of protected health information that may be disclosed for such purposes. See 45 CFR 164.514(d)(3)(i).

Other Public Health Activities. The Privacy Rule recognizes the important role that persons or entities other than public health authorities play in certain essential public health activities. Accordingly, the Rule permits covered entities to disclose protected health information, without authorization, to such persons or entities for the public health activities discussed below.

- Child abuse or neglect. Covered entities may disclose protected health information to report known or suspected child abuse or neglect, if the report is made to a public health authority or other appropriate government authority that is authorized by law to receive such reports. For instance, the social services department of a local government might have legal authority to receive reports of child abuse or neglect, in which case, the Privacy Rule would permit a covered entity to report such cases to that authority without obtaining individual authorization. Likewise, a covered entity could report such cases to the police department when the police department is authorized by law to receive such reports. See 45 CFR 164.512(b)(1)(ii). See also 45 CFR 512(c) for information regarding disclosures about adult victims of abuse, neglect, or domestic violence.

- Quality, safety or effectiveness of a product or activity regulated by the FDA. Covered entities may disclose protected health information to a person subject to FDA jurisdiction, for public health purposes related to the quality, safety or effectiveness of an FDA-regulated product or activity for which that person has responsibility. Examples of purposes or activities for which such disclosures may be made include, but are not limited to:

  - Collecting or reporting adverse events (including similar reports regarding food and dietary supplements), product defects or problems (including problems regarding use or labeling), or biological product deviations;
  - Tracking FDA-regulated products;
  - Enabling product recalls, repairs, replacement or lookback (which includes locating and notifying individuals who received recalled or withdrawn products or products that are the subject of lookback); and
  - Conducting post-marketing surveillance.

  See 45 CFR 164.512(b)(1)(iii). The "person" subject to the jurisdiction of the FDA does not have to be a specific individual. Rather, it can be an individual or an entity, such as a partnership, corporation, or association. Covered entities may identify the party or parties responsible for an FDA-regulated product from the product label, from written material that accompanies the product (known as labeling), or from sources of labeling, such as the Physician's Desk Reference.

- Persons at risk of contracting or spreading a disease. A covered entity may disclose protected health information to a person who is at risk of contracting or spreading a disease or condition if other law authorizes the covered entity to notify such individuals as necessary to carry out public health interventions or investigations. For example, a covered health care provider may disclose protected health information as needed to notify a person that (s)he has been exposed to a communicable disease if the covered entity is legally authorized to do so to prevent or control the spread of the disease. See 45 CFR 164.512(b)(1)(iv).

- Workplace medical surveillance. A covered health care provider who provides a health care service to an individual at the request of the individual's employer, or provides the service in the capacity of a member of the employer's workforce, may disclose the individual's protected health information to the employer for the purposes of workplace medical surveillance or the evaluation of work-related illness and injuries to the extent the employer needs that information to comply with OSHA, the Mine Safety and Health Administration (MSHA), or the requirements of State laws having a similar purpose. The information disclosed must be limited to the provider's findings regarding such medical surveillance or work-related illness or injury. The covered health care provider must provide the individual with written notice that the information will be disclosed to his or her employer (or the notice may be posted at the worksite if that is where the service is provided). See 45 CFR 164.512(b)(1)(v).

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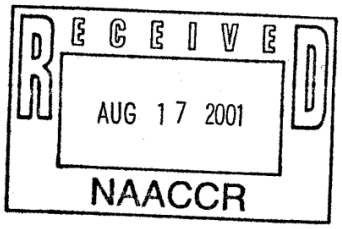

Holly L. Howe, PhD.
Executive Director
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Re: ***The Federal Privacy Rule's Application to Central Cancer Registries***

Dear Dr. Howe:

At your request, we have reviewed the letter dated July 13, 2001, which you received from Professor James Hodge of the Georgetown University Law Center. As discussed by Professor Hodge, federal regulations, entitled *Standards for Privacy of Individually Identifiable Health Information* (the "Privacy Rule"), restrict the use and disclosure of health information by health care providers, health plans, and health care clearinghouses.[1] After reviewing the relevant regulations, Professor Hodge concluded that the Privacy Rule does not restrict the disclosure of patient information by a health care provider to a central cancer registry so long as the central cancer registry is a "public health authority." We agree with that conclusion.

On July 6, 2001, the U.S. Department of Health and Human Services ("DHHS") issued its Guidance on the Privacy Rule and on the issue addressed by Professor Hodge.[2] DHHS concluded that disclosures to public health authorities are permitted under the Privacy Rule, and among various Questions and Answers, stated:

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[1] 45 C.F.R. § 164.500 *et. seq.*

[2] *Guidance on Standards for Privacy of Individually Identifiable Health Information*, issued by the U.S. Department of Health and Human Services, at pg. 54 (July 6, 2001).

Q: Must a health care provider or other covered entity obtain permission from a patient prior to notifying public health authorities of the occurrence of a reportable disease?

A: No. All states have laws that require providers to report cases of specific diseases to public health officials. The Privacy Rule allows disclosures that are required by law. Furthermore, disclosures to public health authorities that are authorized by law to collect or receive information for public health purposes are also permissible under the Privacy Rule. In order to do their job of protecting the health of the public, it is frequently necessary for public health officials to obtain information about the persons affected by a disease. In some cases they may need to contact those affected in order to determine the cause of the disease to allow for actions to prevent further illness.

> The Privacy Rule continues to allow for the existing practice of sharing [protected health information] with public health authorities that are authorized by law to collect or receive such information to aid them in their mission of protecting the health of the public. Examples of such activities include those directed at the reporting of disease or injury, reporting deaths and births, investigating the occurrence and cause of injury and disease, and monitoring adverse outcomes related to food, drugs, biological products and dietary supplements. (emphasis added).

As explained by DHHS in its Guidance, the Privacy Rule allows disclosure of information to public health authorities. With respect to the disclosure of information to central cancer registries, and as noted by Professor Hodge, whether the Privacy Rule restricts the disclosure of information depends on whether each central cancer registry falls within the definition of a "public health authority." A public health authority is defined as:

> an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency...that is responsible for public health matters as part of the official mandate.[3] (emphasis added).

[3] 45 C.F.R. §164.501

Since state cancer registries come within this definition, the Privacy Rule does not restrict disclosure of patient information to them. For the exemption to apply to a non-governmental registry, however, the registry must operate pursuant to a contract with a public agency or under a grant of authority from a public agency.

Should you have any further questions regarding this issue, please advise.

Very truly yours,

Jeffery M. Wilday

JMW:ddh

APPPENDIX B:

Chapter 16-5A-2a of the West Virginia Code and Title 64, West Virginia Administrative Rules, Division of Health, Cancer Registry, Series 68

§16-5A-2a. Cancer and tumor registry.

(a) To the extent funds are available, the director of the division of health shall establish a cancer and tumor registry for the purpose of collecting information concerning the incidence of cancer and nonmalignant intracranial and central nervous system tumors. The information collected by the registry shall be analyzed to prepare reports and perform studies as necessary when such data identifies hazards to public health. Pending appropriate funding, a statewide system shall be phased in and be fully operational by the first day of July, two thousand two, pursuant to the enactment of this section in two thousand one.

(b) All reporting sources, including hospitals, physicians, laboratories, clinics or other similar units diagnosing or providing treatment for cancer and nonmalignant intracranial and central nervous system tumors, shall provide a report of each cancer or tumor case to the cancer and tumor registry in a format specified by the director. The reporting sources shall grant the director or an authorized representative of the registry access to all records which would identify cases of cancer or nonmalignant intracranial and central nervous system tumors or would establish characteristics of cancer or nonmalignant intracranial or central nervous system tumors.

(c) All information reported pursuant to this section is confidential and shall be used for the purpose of determining the sources of malignant neoplasms and nonmalignant intracranial and central nervous system tumors and evaluating measures designed to eliminate, alleviate or ameliorate their effect. A report provided to the cancer and tumor registry disclosing the identity of an individual who was reported as having cancer or tumors shall only be released to reporting sources and persons demonstrating a need which is essential to health-related research, except that the release shall be conditioned upon the reporting source and personal identities remaining confidential. No liability of any kind or character for damages or other relief shall arise or be enforced against any reporting source by reason of having provided the information or material to the cancer and tumor registry.

(d) The director of the division of health shall appoint an advisory committee on cancer and tumors with membership consisting of representatives of appropriate agencies, including the West Virginia hospital association; the American cancer society, West Virginia division; the American lung association of West Virginia; the West Virginia medical association; the association of osteopathic medicine; the West Virginia nurses association; the Mary Babb Randolph cancer center; and, at the discretion of the director, any other individuals directly involved. The advisory committee shall provide technical guidance regarding the operation of the cancer registry and shall provide such advice and assistance as needed to carry out effective cancer prevention and control activities. The members of the advisory committee shall serve four-year terms. Vacancies shall be filled in a like manner for the unexpired term.

(e) The director shall promulgate rules related to: (1) The content and design of all forms and reports required by this section; (2) the procedures for disclosure of information gathered by the cancer and tumor registry by monitoring and evaluating health data and from completed risk assessments; and (3) any other matter necessary to the administration of this section.

TITLE 64
LEGISLATIVE RULE
BUREAU FOR PUBLIC HEALTH
DEPARTMENT OF HEALTH AND HUMAN RESOURCES

SERIES 68
CANCER REGISTRY

§64-68-1. General.

1.1. Scope. -- This legislative rule establishes standards and procedures for reporting cancer cases to the West Virginia Cancer Registry, maintaining the confidentiality of information in its cancer registry and disclosing information from the cancer registry.

1.2. Authority. -- W. Va. Code §§16-1-4, 16-1-11(a) and 16-5A-2a(e).

1.3. Filing Date. -- April 11, 2014.

1.4. Effective Date. -- May 11, 2014.

§64-68-2. Application and Enforcement.

2.1. Application. -- This rule applies to health care providers, health care facilities and persons with access to or in charge of medical records or other sources of cancer-related information.

2.2. Enforcement. -- This rule is enforced by the commissioner of the bureau for public health.

§64-68-3. Definitions.

3.1. Abstract -- A summary of information relating to the diagnosis and course of disease of an individual case of cancer.

3.2. Bureau – The bureau for public health in the department of health and human resources.

3.3. Cancer -- A cellular tumor, the natural course of which is fatal and usually associated with the formation of secondary tumors.

3.4. Cancer Registry -- A registry maintained for the collection of information concerning newly diagnosed cancer cases.

3.5. Commissioner -- The commissioner of the bureau for public health in the department of health and human resources or his or her designee.

3.6. Confidential Information -- Information which identifies individual cancer patients, health care facilities or health care providers.

3.7. Data linkages – The service that the Bureau provides to cancer researchers or other qualified individuals or health care facilities that involves the linkage of an external data file to individual level data maintained in the West Virginia Cancer Registry.

3.8. Diagnosis -- The determination of the nature of a case of disease.

3.9. Health Care Facility -- Any hospital, nursing home, clinic, cancer treatment center, laboratory, or any other facility or institution which provides health care or diagnostic services to individuals.

3.10. Health Care Provider -- Any physician, dentist, nurse, or other individual who provides to individuals medical, dental, nursing, or other health care services of any kind.

3.11. Hospital -- An entity subject to licensure as a hospital under WV Code §16-5B-1.

3.12. Person -- An individual, partnership, corporation or other legal entity.

3.13. Reportable Cancer Case -- Any case of cancer diagnosed after December 31, 1992, where the primary tumor is determined to be malignant or carcinoma in situ, with the exception of basal cell or squamous cell carcinomas of the skin and carcinoma in situ of the cervix.

3.14. Reporting Source -- A health care facility or provider which diagnoses or provides treatment for cancer.

3.15. West Virginia Cancer Registry -- The office within the bureau for public health which collects and maintains information on cancer cases.

§64-68-4. Reporting.

4.1. All reporting sources shall provide the West Virginia Cancer Registry with the following patient-related information on all reportable cancer cases to the extent that the information would be routinely available at a particular type of reporting source:

4.1.a. The last name, first name, and middle initial;

4.1.b. Social security number;

4.1.c. Sex;

4.1.d. Birth date;

4.1.e. Maiden name;

4.1.f. Race/ethnicity;

4.1.g. Physical address at the time of diagnosis, including street, city, county and zip code, state and country or the mailing address at the time of diagnosis if physical address is unavailable;

4.1.h. Date of diagnosis;

4.1.i. A description of the cancer, including site, type, and any other information needed to describe the case clearly;

4.1.j. Stage of disease at diagnosis using:

4.1.j.1. Surveillance, Epidemiology, and End Results (SEER) system;

4.1.j.2. American Joint Committee on Cancer (AJCC) system if maintained by the reporting source; and

4.1.j.3. Collaborative Stage Data Collection System.

4.1.k. The treatment of the cancer and the patient's medical status;

4.1.l. Date of death, if the patient has died;

4.1.m. Cause of death;

4.1.n. Usual occupation;

4.1.o. Usual industry of employment;

4.1.p. Name of patient's health insurance provider;

4.1.q. Marital status;

4.1.r. Other information relevant for the identification of hazards to the public, i.e., the presence of factors placing the patient at risk for development of cancer. Risk factor information includes, but is not limited to: tobacco use, familial history of cancer and alcohol use; and

4.1.s. Other data elements required by the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR).

4.2. Each cancer case report shall also include:

4.2.a. The name of the reporting source;

4.2.b. The name of the diagnosing physician and treating physician; and

4.2.c. Sufficient narrative to determine the accuracy of coding and information.

4.3. Features of Health care facility reporting.

4.3.a. Any health care facility diagnosing or treating cancer patients within the state of West Virginia shall submit the required information on all reportable cases of cancer served by that facility to the West Virginia Cancer Registry within six months of diagnosis.

4.3.b. Reports shall be submitted monthly via electronic information transfer or paper copy of case abstracts, in a manner or on forms acceptable to the West Virginia Cancer Registry.

4.3.c. If the health care facility fails to report in a format prescribed by the commissioner, authorized West Virginia Cancer Registry personnel may enter the health care facility, access the information and report it in the appropriate format. In these cases, the bureau for public health shall assess the health care facility a service fee for accessing and reporting the information. In accordance with WV Code §16-1-11(a) and this rule, the fee collected shall be deposited into the health services fund. The fee shall be based upon the fair market value of the services. The health care facility shall pay the bureau within sixty days of assessment of the fee.

4.4. Health care facilities shall provide authorized West Virginia Cancer Registry personnel access to all medical records which would identify cases of cancer or establish characteristics of cancer to collect the required information on reportable cases of cancer for the purposes of assuring the accuracy and completeness of reported data. Registry staff shall schedule access at reasonable times convenient to the health care facility and registry staff. The West Virginia Cancer Registry staff shall notify the health care facility a minimum of thirty days in advance of its need to access medical records to allow for the health care facility to prepare records for review.

4.5. The West Virginia Cancer Registry shall collect standardized data usable for research purposes.

§64-68-5. Confidentiality; Disclosure.

5.1. No person who obtains information protected by the provisions of WV Code §16-5A-2a and this rule may disclose confidential information to any other person except in strict compliance with WV Code §16-5A-2a and this rule.

5.2. Any person who obtains information protected by the provisions of WV Code §16-5A-2a and this rule shall sign a statement that he or she fully understands and will maintain the confidentiality of the information.

5.3. The West Virginia Cancer Registry may release information which identifies a specific patient to the reporting source which originally reported the cancer case.

5.4. The West Virginia Cancer Registry may release information which identifies a specific patient whose address at the time of diagnosis was outside West Virginia to the central cancer registry in the state where the patient resides. The West Virginia Cancer Registry shall release the information only to central cancer registries in states which have confidentiality standards equivalent to those of West Virginia and which establish reciprocal reporting with West Virginia. The West Virginia Cancer Registry shall have a written agreement with other state cancer registries to which it releases information which specifically addresses provisions for maintaining confidentiality.

5.5. The West Virginia Cancer Registry may release case data to cancer researchers for the purposes of cancer prevention, control and research.

5.5.a. Identifying data may be released for research purposes provided:

5.5.a.1. The researcher supplies the West Virginia Cancer Registry with written consent of the patient, physician, health care provider or personal representative of a deceased case, whichever is appropriate; and

5.5.a.2. The researcher assures that the data received from the West Virginia Cancer Registry will be maintained by the researcher with the same level of confidentiality as that maintained by the West Virginia Cancer Registry.

5.5.b. In accordance with the provisions of the Legislative rule on Reportable Diseases, Events and Conditions, 64CSR7, the West Virginia Cancer Registry may contact individual patients who have cancer and are in the West Virginia Cancer Registry for the purpose of patient recruitment for a research study.

5.5.c. The West Virginia Cancer Registry may provide data linkages to appropriate researchers or institutions to allow for the meaningful use of cancer registry data for a fee. The fee shall be eight hundred dollars ($800.00) per linkage and a fifty dollar ($50.00) per hour assessment for the bureau employee staff time associated with completing the data linkage. The fee shall be assessed and collected by the Office of Epidemiology and Prevention Services of the bureau and shall be deposited into the health services fund.

§64-68-6. Violations and Sanctions.

Failure to comply with this rule as required subjects a person to the criminal penalties prescribed in WV Code §16-1-18.

§64-68-7. Administrative Due Process.

Those persons adversely affected by the enforcement of this rule desiring a contested case hearing to determine any rights, duties, interests or privileges shall do so in a manner prescribed in the bureau for public health Rules of Procedure for Contested Case Hearings and Declarator

APPPENDIX C:

ICD-10-CM Casefinding Codes

WVCR CASEFINDING IN MEDICAL RECORDS

COMPREHENSIVE ICD-10-CM Casefinding Code List for Reportable Tumors

Please refer to your standard setter(s) for specific reporting requirements before using the Casefinding list

ICD-10-CM CODE^	EXPLANATION OF ICD-10-CM CODE
C00.- - C43.- C4A.-	Malignant neoplasms (excluding category C44)
C45.- - C96.- C49.A-	Malignant neoplasms NEW: C49.A-, Gastrointestinal Stromal Tumors, Effective 10/1/2016
C44.00, C44.09	Unspecified/other malignant neoplasm of skin of lip
C44.10-, C44.19-	Unspecified/other malignant neoplasm of skin of eyelid
C44.20-, C44.29-	Unspecified/other malignant neoplasm skin of ear and external auricular canal
C44.30-, C44.39-	Unspecified/other malignant neoplasm of skin of other/unspecified parts of face
C44.40, C44.49	Unspecified/other malignant neoplasm of skin of scalp & neck
C44.50-, C44.59-	Unspecified/other malignant neoplasm of skin of trunk
C44.60-, C44.69-	Unspecified/other malignant neoplasm of skin of upper limb, incl. shoulder
C44.70-, C44.79-	Unspecified/other malignant neoplasm of skin of lower limb, including hip
C44.80, C44.89	Unspecified/other malignant neoplasm of skin of overlapping sites of skin
C44.90, C44.99	Unspecified/other malignant neoplasm of skin of unspecified sites of skin
D00.- - D09.-	In-situ neoplasms (*Note: Carcinoma in situ of the cervix (CIN III-8077/2) and Prostatic Intraepithelial Carcinoma (PIN III-8148/2) are not reportable*).
D18.02	Hemangioma of intracranial structures and any site
D18.1	Lymphangioma, any site (*Note: Includes Lymphangiomas of Brain, Other parts of nervous system and endocrine glands, which are reportable*)
D32.-	Benign neoplasm of meninges (cerebral, spinal and unspecified)
D33.-	Benign neoplasm of brain and other parts of central nervous system
D35.2 - D35.4	Benign neoplasm of pituitary gland, craniopharyngeal duct and pineal gland
D42.-, D43.-	Neoplasm of uncertain or unknown behavior of meninges, brain, CNS
D44.3 - D44.5	Neoplasm of uncertain or unknown behavior of pituitary gland, craniopharyngeal duct and pineal gland
D45	Polycythemia vera (9950/3)

D46.-	Myelodysplastic syndromes (9980, 9982, 9983, 9985, 9986, 9989, 9991, 9992)
D47.1	Chronic myeloproliferative disease (9963/3)
D47.3	Essential (hemorrhagic) thrombocythemia (9962/3)
D47.4	Osteomyelofibrosis (9961/3)
D47.9	Neoplasm of uncertain behavior of lymphoid, hematopoietic and related tissue, unspecified (9970/1, 9931/3)
D47.Z_	Neoplasm of uncertain behavior of lymphoid, hematopoietic and related tissue, unspecified (9960/3, 9970/1, 9931/3)
D49.6, D49.7	Neoplasm of unspecified behavior of brain, endocrine glands and other CNS
R85.614	Cytologic evidence of malignancy on smear of anus
R87.614	Cytologic evidence of malignancy on smear of cervix
R87.624	Cytologic evidence of malignancy on smear of vagina

APPENDIX D:

Acute Care and Critical Access Hospitals in West Virginia

NAME	ADDRESS	CITY	ZIP	PHONE	TYPE
Beckley ARH Hospital	306 Stanaford Road	Beckley	25801	(304) 255-3456	Acute Care
Beckley VA Medical Center	200 Veteran's Avenue	Beckley	25801	(304) 255-2121	Veterans Affairs
Berkeley Medical Center (UHC)	2500 Hospital Drive	Martinsburg	25401	(304) 264-1000	Acute Care
Bluefield Regional Medical Center	500 Cherry Street	Bluefield	24701	(304) 327-1700	Acute Care
Boone Memorial Hospital	701 Madison Avenue	Madison	25130	(304) 369-1230	Critical Access
Braxton County Memorial Hospital	100 Hoylman Drive	Gassaway	26624	(304) 364-5156	Critical Access
Broaddus Hospital (Davis Healthcare)	1 Healthcare Drive	Philippi	26416	(304) 457-1760	Critical Access
Cabell-Huntington Hospital, Inc.	1340 Hal Greer Boulevard	Huntington	25701	(304) 526-2000	Acute Care
CAMC – Teays Valley Hospital	1400 Hospital Drive	Hurricane	25526	(304) 757-1700	Acute Care
Camden Clark Memorial Hospital	800 Garfield Avenue	Parkersburg	26101	(304) 424-2111	Acute Care
Charleston Area Medical Center	501 Morris Street	Charleston	25301	(304) 388-6203	Acute Care
Davis Memorial Hospital	P O Box 1484	Elkins	26241	(304) 636-3300	Acute Care
Fairmont General Hospital	1325 Locust Avenue	Fairmont	26554	(304) 367-7100	Acute Care
Grafton City Hospital	500 Market Street	Grafton	26354	(304) 265-0400	Critical Access
Grant Memorial Hospital	117 Hospital Drive	Petersburg	26847	(304) 257-1026	Acute Care
Greenbrier Valley Medical Center	202 Maplewood Avenue	Ronceverte	24970	(304) 647-4411	Acute Care
Hampshire Memorial Hospital	549 Center Avenue	Romney	26757	(304) 822-4561	Critical Access
Huntington VA Medical Center	1540 Spring Drive	Huntington	25704	(304) 429-6741	Veterans Affairs
Jackson General Hospital	122 Pinnell Street	Ripley	25271	(304) 373-1474	Acute Care
Jefferson Medical Center (UHC)	300 South Preston Street	Ranson	25438	(304) 728-1600	Critical Access

Logan Regional Medical Center	20 Hospital Drive	Logan	25601	(304) 831-1350	Acute Care
Louis A. Johnson VA Medical Center	1 Medical Center Drive	Clarksburg	26301	(304) 623-3461	Veterans Affairs
Martinsburg VA Medical Center	510 Butler Avenue	Martinsburg	25405	(304) 263-0811	Veterans Affairs
Minnie Hamilton	Route 1 Box 1A	Grantsville	26147	(304) 354-9244	Critical Access
Monongalia General Hospital	1200 JD Anderson Drive	Morgantown	26505	(304) 598-1200	Acute Care
Montgomery General Hospital, Inc.	401 Sixth Avenue	Montgomery	25136	(304) 442-5151	Critical Access
Ohio Valley Medical Center	2000 Eoff Street	Wheeling	26003	(304) 234-0123	Acute Care
Plateau Medical Center	430 Main Street	Oak Hill	25901	(304) 469-8600	Critical Access
Pleasant Valley Hospital	2520 Valley Drive	Point Pleasant	25550	(304) 675-4340	Acute Care
Pocahontas Memorial Hospital	RR Box 52 West	Buckeye	24924	(304) 799-7400	Critical Access
Potomac Valley Hospital	167 South Mineral Street	Keyser	26726	(304) 597-1100	Critical Access
Preston Memorial Hospital	300 S Price Street	Kingwood	26537	(304) 329-1400	Critical Access
Princeton Community Hospital	122 Twelfth Street	Princeton	24740	(304) 487-7260	Acute Care
Raleigh General Hospital	1710 Harper Road	Beckley	25801	(304) 256-4100	Acute Care
Reynolds Memorial Hospital	800 Wheeling Avenue	Glen Dale	26038	(304) 843-3230	Acute Care
Roane General Hospital	200 Hospital Drive	Spencer	25276	(304) 927-4444	Critical Access
Sistersville General Hospital	314 South Wells Street	Sistersville	26175	(304) 652-2611	Critical Access
St Francis Hospital (Thomas HS)	333 Laidley Street	Charleston	25301	(304) 347-6500	Acute Care
St Joseph Hospital	1 Amalia Drive	Buckhannon	26201	(304) 472-2000	Acute Care
St Mary's Medical Center	2900 1st Avenue	Huntington	25701	(304) 526-1270	Acute Care
Stonewall Jackson Memorial Hospital	Route 4 Box 10	Weston	26452	(304) 269-8080	Acute Care
Summers County ARH Hospital	Terrace Street	Hinton	25951	(304) 466-1000	Critical Access
Summersville Memorial Hospital	400 Fairview Heights Road	Summersville	26651	(304) 872-2891	Acute Care

Thomas Memorial Hospital	4605 MacCorkle Avenue, SW	South Charleston	25309	(304) 766-3600	Acute Care
United Hospital Center	327 Medical Park Drive	Bridgeport	26330	(681) 342-1000	Acute Care
War Memorial Hospital	1 Healthy Way	Berkeley Springs	25411	(304) 258-1234	Critical Access
Webster County Memorial Hospital	P O Box 312	Webster Springs	26288	(304) 847-5682	Critical Access
Weirton Medical Center	601 Colliers Way	Weirton	26062	(304) 797-6000	Acute Care
Welch Community Hospital	454 McDowell Street	Welch	24801	(304) 436-8461	Acute Care
West Virginia University Hospitals	Medical Center Drive	Morgantown	26506	(304) 598-4000	Acute Care
Wetzel County Hospital	#3 East Benjamin Drive	New Martinsville	26155	(304) 455-8000	Acute Care
Wheeling Hospital	1 Medical Park	Wheeling	26003	(304) 243-3000	Acute Care
Williamson Memorial Hospital	859 Alderson Street	Williamson	25661	(304) 235-2500	Acute Care

APPENDIX E:

New NPCR Requirements for cases diagnosed January 1, 2018 forward

Beginning with cases diagnosed January 1, 2018, the West Virginia Cancer Registry is requiring Directly Assigned SEER Summary 2018 only. TNM data items are still required from facilities accredited by the American College of Surgeons (ACoS).

Additional data items required for cases diagnosed beginning January 1, 2018. Some of this information was previously captured in the Collaborative Stage Site Specific Factors (SSF) prior to 2018 but will now be captured in the Site- Specific Data Items (SSDI) beginning 2018 forward.

- Phase I Radiation Treatment Modality (#1506) will replace Radiation Modality (#1570) and RX Summ—Radiation (#1360)
- Directly assigned Summary Stage 2018 (#762)
- (#3816) Molecular Markers-Brain
- (#3817) Breslow Tumor Thickness-Melanoma,
- (#3827) ERA Summary, (#3915) PRA Summary, (#3855) HER2 Overall Summary-Breast
- (#3835) Fibrosis Score-Liver and Intrahepatic Bile Ducts
- (#3843) Grade Clinical
- (#3890) Microsatellite Instability (MSI)-Colon and Rectum
- (#3920) PSA Lab Value-Prostate
- (#3932) LDH Pretreatment Value-Plasma Cell Myeloma, Plasma Cell Disorders
- (3844) Grade Pathological as available
- (3845) Grade Post Therapy as available
- (#3926) Schema Discriminator 1-
    - BileDuctsDistal/BileDuctsPerihilar/CysticDuct
    - EsophagusGEJunction (EGJ)/Stomach
    - Histology Discriminator for 9591/3
    - Lacrimal Gland/Sac
    - Melanoma Ciliary Body/Melanoma Iris
    - Nasopharynx/Pharyngeal Tonsil C111 only
    - Occult Head and Neck Lymph Nodes
    - Plasma Cell Myeloma Terminology
    - Primary Peritoneum Tumor
    - Thyroid Gland/Thyroglossal Duct
    - Urethra/Prostatic Urethra
- (#3927) Schema Discriminator 2
    - Histology Discriminator for 8020/3
    - Oropharyngeal p16

CDC NPCR SSFs Rerequired for Directly-Assigned AJCC TNM Stage 7th Edition for cases diagnosed Jan. 1, 2016 – Dec. 31, 2017

Site (CS Schema)	SSF	Description
Appendix	SSF 11	Histopathologic Grading
GISTPeritoneum	SSF 5 and 10	Mitotic Count; Location of Primary Tumor
GIST Esophagus, GIST Small Intestine, GIST Stomach	SSF 6	Mitotic Count
GIST Appendix, GIST Colon, GIST Rectum	SSF 11	Mitotic Count
MycosisFungoides	SSF 1	Peripheral Blood Involvement
Placenta	SSF 1	Prognostic Scoring Index
Prostate	SSF 1, 8 and 10	PSA Lab Value, Gleason Score
Testis	SSF 13, 15, 16	Post Orchiectomy AFP, hCG, and LDH Range
BileDuctsDistal, BileDuctsPerihilar, CysticDuct, EsophagusGEJunction, LacrimalGland, LacrimalSac, Melanoma CiliaryBody, MelanomaIris, Nasopharynx, PharyngealTonsil, Stomach	SSF 25	Schema Discriminator
Brain, CNS Other, Intracranial	SSF 1	WHO Grade
Breast	SSF 1	ERA
	SSF 2	PRA
	SSF 8	HER2: IHC Value
	SSF 9	HER2: IHC Interpretation
	SSF 11	HER2: FISH Interpretation
	SSF 13	HER2: CISH Interpretation
	SSF 14	HER2: Result of other test
	SSF 15	HER2: Summary Result
	SSF 16	testing Combination of ERA, PRA and HER2 Testing