Case Reporting Requirements

CASES TO BE REPORTED:

All cases of primary malignant disease diagnosed or treated at a Kentucky health care facility on or after January 1, 1991, should be reported to the Kentucky Cancer Registry (KCR). These are usually described by the terms: carcinoma, sarcoma, melanoma, leukemia, or lymphoma. Reportable cases may be identified by specified ICD-10-CM codes. Refer to Casefinding for a list of these codes. They may also be classified by ICD-O topography, morphology, and behavior codes. Effective with diagnoses in 2010, all hematopoietic and lymphoid neoplasms classified with a behavior code 3 in the "WHO Classification of Tumors of Hematopoietic and Lymphoid Tissues" are reportable. These fall into the histology code range of 9590/3 - 9992/3. Only in-situ and malignant neoplasms are reportable (behavior codes 2 and 3); benign, borderline, and metastatic tumors are not reportable to Kentucky Cancer Registry, except as noted below.

However, if a term is used which usually has a behavior code of '0' or '1', but is verified by a pathologist as in-situ or malignant (behavior code 2 or 3), these cases are reportable. Refer to SEER Appendix E.1 for reportable and non-reportable examples.

THE ONLY EXCEPTIONS to this are:

- Neoplasms of the skin (ICD-O Topography codes C44.0 to C44.9) with the following ICD-O Morphology codes are NOT reportable:

M 8000-8005 Neoplasms, NOS

M 8010-8046 Epithelial neoplasms

M 8050-8084 Squamous cell neoplasms of the skin

M 8090-8110 Basal cell neoplasms of the skin

NOTE: Localized basal and squamous cell skin cancers greater than 5 cm at diagnosis, as well as those diagnosed at a regional or distant stage, were previously required by ACoS for approved hospitals prior to 2003. **They are not required to be reported to KCR or to ACoS <u>after</u> January 1, 2003.**

1. Malignant Histologies (In Situ and Invasive)

a. Report all histologies with a behavior code of /2 or /3 in the ICD-O- Third Edition, Second Revision Morphology (ICD-O-3.2) PLUS the ICD-O-3.2 updates posted on the NAACCR website (Appendix E), except as noted in section 1.b. below

i. Clear cell papillary renal cell carcinoma (8323/3) is reportable

ii. Low-grade appendiceal mucinous neoplasm (LAMN) is reportable (as of 1/1/2022).

iii. Early or evolving melanoma, in situ and invasive: As of 01/01/2021, early or evolving melanoma in situ, or any other early or evolving melanoma, is reportable.

iv. All GIST tumors, except for those stated to be benign, are reportable as of 01/01/2021. The behavior code is /3 in ICD-O-3.2.

v. Nearly all thymomas are reportable as of 01/01/2021. The behavior code is /3 in ICD-O-3.2. The exceptions are:

- Microscopic thymoma or thymoma, benign (8580/0)
- Micronodular thymoma with lymphoid stroma (8580/1)
- Ectopic hamartomatous thymoma (8587/0)

vi. Carcinoid, NOS of the appendix is reportable. As of 01/01/2015, the ICD-O-3 behavior code changed from /1 to /3.

vii. The following diagnoses are <u>reportable</u> (not a complete list)

- Lobular carcinoma in situ (LCIS) of breast
- Intraepithelial neoplasia, high grade, grade II, grade III

Examples: (Not a complete list. See 1.b.iii for PIN III.)

- Anal intraepithelial neoplasia II (AIN II) of the anus or anal canal (C210-C211)
- Anal intraepithelial neoplasia III (AIN III) of the anus or anal canal (C210-C211)
- Biliary intraepithelial neoplasia, high grade
- Differentiated vulvar intraepithelial neoplasia (VIN)
- Endometrioid intraepithelial neoplasia
- Esophageal intraepithelial neoplasia (dysplasia), high grade (as of 1/1/2024)
- Glandular intraepithelial neoplasia, high grade
- Intraductal papillary neoplasm with high grade intraepithelial neoplasia

- Intraepithelial neoplasia, grade III
- Laryngeal intraepithelial neoplasia II (LIN II) (C320-C329)
- Laryngeal intraepithelial neoplasia III (LIN III) (C320-C329)
- Lobular neoplasia grade II (LN II)/lobular intraepithelial neoplasia grade II (LIN II) breast (C500-C509)
- Lobular neoplasia grade III (LN III)/lobular intraepithelial neoplasia grade III (LIN III) breast (C500-C509)
- Pancreatic intraepithelial neoplasia (PanIN II) (C250-C259)
- Pancreatic intraepithelial neoplasia (PanIN III) (C250-C259)
- Penile intraepithelial neoplasia, grade II (PeIN II) (C600-C609)
- Penile intraepithelial neoplasia, grade III (PeIN III) (C600-C609)
- Squamous intraepithelial neoplasia, grade II excluding cervix (C53_) and skin sites coded to C44_
- Squamous intraepithelial neoplasia III (SIN III) excluding cervix (C53_) and skin sites coded to C44_
- Vaginal intraepithelial neoplasia II (VAIN II) (C529)
- Vaginal intraepithelial neoplasia III (VAIN III) (C529)
- Vulvar intraepithelial neoplasia II (VIN II) (C510-C519)
- Vulvar intraepithelial neoplasia III (VIN III) (C510-C519)

viii. Report Pilocytic/Juvenile astrocytomas; code the histology and behavior as 9421/3

Exception: The behavior is non-malignant when the primary site is optic nerve (C723).

ix. Non-invasive mucinous cystic neoplasm (MCN) of the pancreas with high grade dysplasia is reportable. For neoplasms of the pancreas, the term MCN with high grade dysplasia replaces the term mucinous cystadenocarcinoma, non-invasive.

x. Mature teratoma of the testes in adults is malignant and reportable as 9080/3

xi. Urine cytology positive for malignancy is reportable for diagnoses in 2013 and forward

- Exception: When a subsequent biopsy of a urinary site is negative, do not report.
- Code the primary site to C689 in the absence of any other information
- Do not implement new/additional casefinding methods to capture these cases
- Do not report cytology cases with ambiguous terminology (see page 9 for ambiguous terms)

b. Do <u>not</u> report (Exceptions to reporting requirements)

i. Skin primary (C440-C449) with any of the following histologies

Malignant neoplasm (8000-8005)

Epithelial carcinoma (8010-8046)

Papillary and squamous cell carcinoma (8050-8084)

Squamous intraepithelial neoplasia III (SIN III) (8077) of skin sites coded to C44_

Basal cell carcinoma (8090-8110)

ii. In situ carcinoma of cervix (/2), any histology, cervical intraepithelial neoplasia (CIN III), or SIN III of the cervix (C530-C539)

Note: Collection stopped effective with cases diagnosed 01/01/1996 and later. As of the 2018 data submission, <u>cervical in situ cancer is no longer required for any diagnosis year.</u> Sequence all cervix in situ cases in the 60-87 range regardless of diagnosis year.

iii. Prostatic intraepithelial neoplasia (PIN III) (C619)

Note: Collection stopped effective with cases diagnosed 01/01/2001 and later.

iv. Colon atypical hyperplasia

v. High grade dysplasia in colorectal

vi. Adenocarcinoma in situ, HPV associated (8483/2)(C53)

2. Benign/Non-Malignant Histologies

a. Report benign and borderline primary intracranial and central nervous system (CNS) tumors with a behavior code of /0 or /1 in ICD-O-3 (effective with cases diagnosed 01/01/2004 to 12/31/2020) or ICD-O-3.2 (effective with cases diagnosed 01/01/2021 and later). See the table below for the specific sites.

Note 1: Benign and borderline tumors of the cranial bones (C410) are not reportable.

Note 2: Benign and borderline tumors of the peripheral nerves (C47_) are not reportable.

b. Report pilocytic astrocytoma/juvenile pilocytic astrocytoma as 9421/1 for all CNS sites as of 01/01/2023

c. Report diffuse astrocytoma, MYB- or MYBL1-altered and diffuse low-grade glioma, MAPK pathway-altered (9421/1) as of 01/01/2023

d. Report multinodular and vacuolating neuronal tumor (9509/0) as of 01/01/2023

e. Report juvenile xanthogranuloma (9749/1) as of 01/01/2023 (C715 is the most common site)

f. Neoplasm and tumor are reportable terms for intracranial and CNS because they are listed in ICD-O-3.2 with behavior codes of /0 and /1

i. “Mass” and “lesion” are not reportable terms for intracranial and CNS because they are not listed in ICD-O-3.2 with behavior codes of /0 or /1

General Term	Specific Sites	ICD-O-3 Topography Code
Meninges	Cerebral meninges	C700
	Spinal meninges	C701
	Meninges, NOS	C709
Brain	Cerebrum	C710
	Frontal lobe	C711
	Temporal lobe	C712
	Parietal lobe	C713
	Occipital lobe	C714
	Ventricle, NOS	C715
	Cerebellum, NOS	C716
	Brain stem	C717
	Overlapping lesion of brain	C718
	Brain, NOS	C719
Spinal cord, cranial nerves, and other parts of the central nervous system	Spinal cord	C720
	Cauda equina	C721
	Olfactory nerve	C722
	Optic nerve	C723
	Acoustic nerve	C724
	Cranial nerve, NOS	C725
	Overlapping lesion of brain and central nervous system	C728
	Nervous system, NOS	C729
Pituitary, craniopharyngeal duct, and pineal gland	Pituitary gland	C751
	Craniopharyngeal duct	C752
	Pineal gland	C753

PATIENTS TO BE REPORTED:

All patients first seen and/or treated at each Kentucky hospital after January 1, 1991 for a diagnosis of cancer should be reported to the Kentucky Cancer Registry. This includes inpatient admissions and patients seen in ambulatory care settings that are hospital affiliated. It includes all clinical diagnoses of cancer, whether histologically confirmed or not. It also includes patients diagnosed as autopsy.

As of January 1, 1995, all patients seen or treated in any licensed health facility in the state, which provides diagnostic or treatment services to cancer patients, shall report cases to the Kentucky Cancer Registry. Physicians in private practice should report any cases of cancer diagnosed or treated in their offices which are not otherwise reported to KCR by another health care facility.

PATIENTS NOT REQUIRED TO BE REPORTED BY HOSPITALS:

1. Patients who are seen only in consultation to confirm a cancer diagnosis or treatment plan, and no treatment was provided by your facility.

EXAMPLE: Patient comes to your institution for a second opinion. Staff physicians order diagnostic tests. The physicians support the original treatment plan. Patient returns to the other institution for treatment.

2. Patients who receive transient care to avoid interrupting a course of therapy initiated elsewhere, for example, while vacationing, or because of equipment failure at the original hospital.

3. Patients whose medical chart indicates a history of cancer only, and who were diagnosed prior to 1991.

4. Patients with in-situ or localized neoplasms of the skin (as listed above).

5. Patients with preinvasive neoplasia of the cervix (as listed above).

TIME FRAME FOR REPORTING:

Cases must be reported to the KCR within 6 months from the date of initial diagnosis or date first seen at the reporting facility if not diagnosed there. For those patients seen on an outpatient basis only, the outpatient visit date is considered the date of discharge.

CLASSES OF CASE:

The class of case codes as defined by the American College of Surgeons in their Facility Oncology Registry Data Standards (FORDS) manual, describe categories (or classes) of cases based on the facility's role in managing the cancer, whether the cancer is required to be reported, and whether the case was diagnosed after the program's reference date. The reporting requirements of the Kentucky Cancer Registry may differ from those of the American College of Surgeons. For a discussion of ACoS requirements, refer to the FORDS manual.

Class of Case divides cases into two groups. Analytic cases (codes 00–22) are those that are required by CoC to be abstracted because of the program's primary responsibility in managing the cancer. Nonanalytic cases (codes 30–49 and 99) may be abstracted by the facility to meet central registry requirements or in response to a request by the facility's cancer program.

KCR requires all analytic cases (class 00-22) as well as autopsy only cases (class 38) to be fully abstracted and reported to KCR. In addition, cases of VIN III, VAIN III, AIN III (8077/2), PeIN III, LIN III, LN III, and SIN III, though not required by COC, are required to be reported to SEER and KCR. Therefore, these cases should be coded in the analytic classes (00-22) rather than 34 or 36. They will automatically be excluded from transmission to NCDB by CPDMS.net. KCR also requires information about non-analytic cases (class 32 and 40-43) to be reported to KCR. See Section below: INFORMATION TO BE REPORTED TO KCR.

In the 2010 class of case conversion, skin cancers which were reportable prior to 2003 and CIN/CIS of the cervix diagnosed prior to 1998 are converted to class 34 or 36, as applicable. See Class of Case for a comprehensive list of all classes of cases.

INFORMATION TO BE REPORTED TO KCR:

Cases in classes 00-22 and 38 must be fully abstracted in CPDMS.net. All mandatory data elements must be filled in. Detailed instructions for completing the Abstract Form can be found in this manual.

These cases must also be followed annually throughout the life of the patient. A comprehensive method to identify and track patients must be implemented by the reporting hospital. The follow up information that is required to be reported is detailed in items Follow Up. The only exceptions to the follow up requirements are patients residing in foreign countries and patients with carcinoma in situ of the cervix. These two categories of patients are not required to be followed, regardless of class of case. The ACoS does not require CoC approved hospitals to follow patients over 100 years of age. However, KCR requires Kentucky hospitals to follow <u>all</u> patients in classes 00-22, regardless of age.

Cases diagnosed prior to January 1, 2000, which are class 32 (formerly class 3 before 2010) must be reported to KCR. Effective with year 2000 diagnoses, registries have a choice in reporting class 32 cases to KCR. Facilities may choose to continue abstracting these cases, or instead they may send the case information to KCR to be abstracted. If your registry chooses to forward the case to KCR, you are still required to send all applicable case information to KCR in a timely manner!

Cases in class 37 (formerly class 4 prior to 2010) are not required to be reported to the Kentucky Cancer Registry. Abstracting the case and lifetime follow up are entirely optional.

Cases in class 49 (formerly class 8 prior to 2010) are those discovered through death certificate files only. KCR staff will abstract these cases. Class 49 is only for use by the central registry.

Cases in class 99 (formerly class 9 prior to 2010) are nonhospital facility cases. Class 99 is only for use by the central registry. NOTE: If your hospital has read an outside pathology report diagnosing cancer, this is not reportable by your facility. However, information regarding the diagnosis MUST be sent to KCR so that the case may be abstracted by nonhospital facility staff.

THERAPY - FIRST AND SUBSEQUENT COURSE

First course of therapy includes any and all procedures or treatments planned by the managing physician(s), and administered during or after the first clinical diagnosis of cancer. Treatment usually modifies, controls, removes, or destroys proliferating cancer tissue, whether primary or metastatic, regardless of the patient's response. First course may include multiple modes of therapy, and may encompass intervals of a year or more.

No therapy is a treatment option that occurs if the patient or family refuses treatment, or the patient dies before treatment starts, or the physician recommends "watchful waiting" or no treatment be given.

When a treatment plan is not available, evaluate the therapy and the time it started. If the therapy is a part of an established protocol or within accepted management guidelines for the disease, it is first course of therapy. Consult the attending physician or registry's physician advisor if protocols or management guidelines are not available.

If there is no treatment plan, established protocol, or management guidelines, and you cannot consult with a physician, use the principle: "initial treatment must begin within four months of the date of initial diagnosis." All other cancer-directed therapy that begins within four months of the date of the initial treatment would be first course of therapy.

TIME FRAME FOR REPORTING FOLLOW-UP INFORMATION:

Current follow-up information must be reported to KCR for every case diagnosed since 1995 that is class 00-22. Follow-up information is considered current if the date of last contact with the patient is within 15 months of the current date. CPDMS.net can generate reports which identify patients who require updated follow-up information.