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**Rules of**  
**Department of Health**  
**Division 70—Division of Chronic Disease**  
**Prevention and Health Promotion**  
**Chapter 21—Cancer**

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**Title 19—DEPARTMENT OF  
HEALTH**

**Division 70—Division of Chronic Disease  
Prevention and Health Promotion  
Chapter 21—Cancer**

**19 CSR 70-21.010 Reporting of Cancer  
Cases**

*PURPOSE: This rule establishes a method of mandatory reporting of all cancer cases of inpatients and outpatients in order to conduct cancer incidence surveillance and epidemiologic studies and to facilitate development, implementation and evaluation of cancer prevention and control measures in Missouri as required by sections 192.650, 196.653, 192.655 and 192.657, RSMo Supp. 1999.*

*PUBLISHER'S NOTE: The publication of the full text of the material that the adopting agency has incorporated by reference in this rule would be unduly cumbersome or expensive. Therefore, the full text of that material will be made available to any interested person at both the Office of the Secretary of State and the office of the adopting agency, pursuant to section 536.031.4, RSMo. Such material will be provided at the cost established by state law.*

(1) The following are definitions of terminology used throughout this rule.

(A) Cancer—those malignant neoplasms included in the list of cancers with a fifth digit of two or three listed under the heading, “Morphology of Neoplasms,” contained in the current editions of “International Classification of Diseases” (ICD) or “International Classification of Diseases for Oncology” (ICD-O) published by the World Health Organization.

(B) Department—the Missouri Department of Health.

(C) Non-melanomatous skin cancers—cutaneous, malignant basal and squamous cell neoplasms as defined in the current edition of the *Missouri Cancer Registry Abstract Code Manual*, which is incorporated by reference in this rule.

(D) State registry—a centralized cancer reporting system maintained by the Missouri Department of Health for the collection, storage, analysis and interpretation of data on cancer patients.

(E) Reporting entity—hospital, pathology laboratory, ambulatory surgical center, free-standing cancer clinic and treatment center, physician office, skilled nursing facility, intermediate care facility or residential care facility I or II.

(F) Case—A primary incidence of cancer. A patient may have more than one primary incidence of cancer.

(2) The administrator or designated representative of a reporting entity shall report every case of cancer—with the exception of non-melanomatous skin cancers—to the director of the department or to the director’s designated representative. Hospitals that electronically report shall use the North American Association of Central Cancer Registries (NAACCR) layout and shall use information provided by the physician to complete the report. Hospitals with more than 75 cases of cancer annually who do not electronically report shall use the paper report format “Cancer Registry Initial Abstract” provided by the state registry and shall use information provided by the physician to complete the report. Hospitals with less than 75 cases of cancer annually who do not electronically report shall use the paper report format “Missouri Cancer Registry Initial Abstract” provided by the state registry completed using information provided by the physician or submit copies of medical record documentation sufficient for abstraction of required cancer incidence data. All non-hospital reporting entities shall report all required data items using the paper form supplied by the state registry or in an electronic format designated by the state registry.

(A) Reports shall be made by the administrator or designated representative of the reporting entity within six months after the diagnosis or within six months after the date of first contact for this primary incidence of cancer at the reporting entity. Coding will be completed as described in the current edition of the *Missouri Cancer Registry Abstract Code Manual*.

(3) All patients seen, diagnosed or treated for cancer for the first time by a physician or other health care provider on an inpatient or outpatient basis are to be reported. Subsequent reports on such patients are not required unless a new primary incidence of cancer is diagnosed.

(A) Physician offices are exempt from reporting cases that are directly referred to or previously have been admitted to any other facility that is required to report as described in subsection (1)(E) above (i.e., hospital, pathology laboratory, ambulatory surgical center, free-standing cancer clinic and treatment center, physician office, skilled nursing facility, intermediate care facility or residential care facility I or II). Physicians may be contacted by the state registry if additional information regarding a directly referred or

previously admitted case is considered necessary for abstraction of required cancer incidence data.

(4) The minimum data reported on each case shall include those data elements required by the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) and years of tobacco use. The department recommends reporting all data elements required and/or recommended by the American College of Surgeons (ACoS), not already included in the NPCR requirements and toxic exposure, the Missouri-specific optional data element.

(5) The department may provide training or written instructions for individuals designated by a reporting entity’s administrator or designated representative to facilitate submission of required information.

(6) A reporting entity is considered compliant if it meets the requirements of sections 192.650 and 192.653, RSMo. A non-compliant reporting entity will be notified in writing as to their non-compliant status within 30 days following the end of the six-month period and will be given an opportunity to take corrective action within 60 days from the date of the notification letter. If the reporting entity does not comply within 60 days, a second notification letter will be sent directing the reporting entity to comply within 30 days.

(7) A researcher requesting data must provide the department with a current curriculum vitae and publication list, indicate in precise detail the data which are desired, provide a copy of the research protocol describing the purpose(s) for which the data are to be used and a copy of their Institutional Review Board (IRB) approval.

(A) In the event the data requested include the identity of any patient, physician, health care provider or reporting entity and provided that the department has determined that identifying data are necessary for the research, has approved it through the department’s IRB and has determined that the research is worthwhile, the researcher must agree in writing to protect the confidentiality of the data and to use such data only for purposes stated in the written agreement and not for any secondary purpose. Identifying data will be released only after consent for this purpose has been obtained from the patient, physician, health care provider or reporting entity—whichever is appropriate—as authorized in section 192.655, RSMo and may not be made available to any other individual, agency, institution, or firm.



(B) No follow-back of any type shall be made to any individual, institution or agency without written authorization by the department. Any data released by a researcher shall be restricted to aggregate data and shall not identify any individual or institution. The department shall be given credit as the source of the data. A copy of the results of the research shall be furnished to the department.

(C) If electronic media are provided, such media, after serving the purpose set forth in this subsection, shall be erased unless specific authority is required and granted for their retention and future use.

(D) The researcher will be billed prior to delivery of the data for a reasonable fee to cover actual costs to the department for retrieving and preparing the requested data, together with costs of postage and handling fees.

(8) The data provided by each reporting entity and single copies of analyses based upon data from that entity will be provided to hospitals in the form of management reports and routine periodic quality control reports at no cost to the hospital for purposes of advancement of research, education and treatment. Management reports and routine periodic quality control reports will be made available upon written request to other reporting entities at no cost.

(A) Single copies of reports summarizing the data from all reporting entities will be provided upon written request to each reporting entity at no cost. Multiple copies will be made available upon receipt of a fee sufficient to cover the cost of reproduction of the document together with postage and handling fees.

(B) Special reports requested by a reporting entity will be made available upon receipt of a fee sufficient to cover the cost of analysis, interpretation, compilation and reproduction of the document together with postage and handling fees.

*AUTHORITY: sections 192.006 and 192.650–192.657, RSMo Supp. 1999.\* This rule was previously filed as 13 CSR 50-115.010, 19 CSR 30-17.010 and 19 CSR 20-21.010. Original rule filed May 11, 1984, effective Aug. 11, 1984. Amended: Filed June 19, 1987, effective Sept. 11, 1987. Rescinded and readopted: Filed June 14, 2000, effective Dec. 30, 2000.*

*\*Original authority: 192.006, RSMo 1993, amended 1995; 192.650-192.657 see Missouri Revised Statutes 2000.*