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

Title Page

19 CSR 70-21.010 Reporting of Cancer Cases

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PURPOSE: This rule establishes a method of mandatory reporting of cancer cases by hospitals to conduct comprehensive epidemiological surveys and to facilitate development and evaluation of cancer prevention and control measures in Missouri as required by sections 192.650, 192.653, 192.655 and 192.657, RSMo (1986).

Editor's Note: The secretary of state has determined that publication of this rule in its entirety would be unduly cumbersome or expensive. The entire text of the rule has been filed with the secretary of state. The entire text of the rule, including the three publications referred to in subsection (1), (4) and sections (2) and (4) of this rule, is also available at the office of the director, section of epidemiology services, Department of Health and is available to any interested person at a cost not more than the actual cost of reproduction.

(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 (2), three (3), six (6) or nine (9) listed under the heading, "Morphology of Neoplasms," contained in the 1976 edition of International Classification of Diseases for Oncology (ICD-O) published by the World Health Organization;

(B) Nonmelanomatous skin cancers—cutaneous, malignant basal and squamous cell neoplasms; and

(C) State registry—a centralized cancer reporting system maintained by the Department of Health for the collection, storage, analysis and interpretation of data on cancer patients. The state registry collects both cancer incidence and cancer survival data.

(2) The chief administrative officer of every hospital shall report every case of cancer—except the exception of nonmelanomatous skin cancer—to the director of the Department of Health or to the director's designated representative, using the paper report format provided by the state registry or a machine-readable tape in the same format and based upon information provided by the attending physician. Reports by the chief administrative officer of any hospital shall be made within four (4) months after the diagnosis or within four (4) months after the first course of therapy administered at the reporting hospital. Missouri hospitals which directly submitted cancer data on computer tape to the Department of Health prior to the effective date of this rule may continue to submit data in the same format, provided all minimum data as listed in section (4) of this rule are reported. Report format will be completed as described in the state registry's July 1984 Incidence Abstract Code Manual.

(3) All patients seen, diagnosed or treated for the first time for cancer by a physician at a hospital after the effective date of this rule—on an inpatient basis—are to be reported. Subsequent reports on these patients are not required unless a new cancer is diagnosed.

(4) The minimum data reported on each case shall include assigned hospital code number; patient's name; patient's medical record number; patient's race and sex; residence at birth; residence at diagnosis; primary past residence; birth date; Social Security number; primary anatomic site written and ICD-O code; histologic type written and ICD-O code; basis of diagnosis; date of diagnosis; code for stage (using SEER system in Summary Staging Guide for the Cancer Surveillance, Epidemiology and End Results Reporting (SEER) Program, National Institutes of Health Publication No. 81-2813, January 1981) and brief written description; method of tumor-directed treatment; personal history of cancer; vital status code (alive/dead; with/without cancer); family history of cancer including relationship to patient and ICD-O site code; any unusual toxic exposure; number of pregnancies or live births for women; level of alcohol use; level of tobacco use; primary lifetime occupation with number of years employed in the primary lifetime occupation; and type of industry.

(5) A researcher requesting data must provide the Department of Health with a current curriculum vitae and publication list, indicate in precise detail the data which are desired and provide a copy of the protocol describing the purpose(s) for which the data are to be used. In the event that the data requested include the identity of any patient, physician or hospital and provided that the Department of Health has determined that identifying data are necessary for the research and that the research is worthwhile, the researcher must agree in writing to protect the confidentiality of the data and to use the data only for purposes stated in the written agreement. Identifying data will be released only after consent for this purpose has been obtained from the patient, physician or hospital— whichever is appropriate—as authorized in section 192.655, RSMo (1986). The researcher will be billed prior to delivery of the data for a reasonable fee to cover actual costs to the Department of Health for retrieving and preparing the requested data, together with costs of postage and handling fees.

(6) If a hospital requests data on patients hospitalized at one (1) or more other hospitals, such a hospital will be asked to identify a qualified researcher and the request will be handled as provided in section (5) of this rule. Qualification of researchers and application of a fee schedule will be determined by the director of the Department of Health.

(7) The data provided by each hospital and single copies of analyses based upon the data from that individual hospital will be provided to the hospital in the form of routine periodic reports and special reports prepared upon the written request of the hospital at no cost to the hospital for purposes of advancement of research, education and treatment. Single copies of periodic reports and special reports summarizing the data from all hospitals will be provided to each hospital 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.

(8) The Department of Health will provide training for individuals designated by the hospital's chief administrative officer to facilitate submission of required information.