



Minnesota Cancer Surveillance System Notes



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MCSS Rulemaking is Underway

The need for accurate information about the occurrence of cancer was recognized by the Minnesota Legislature in 1981, when legislation was introduced to establish a statewide cancer surveillance system. In 1987, following a six-year process which included consensus building, development of methods, and a feasibility study funded by The Bush Foundation, legislation (Minnesota Statutes 144.671-144.69) was passed to establish the Minnesota Cancer Surveillance System (MCSS). MCSS began operations on January 1, 1988. Currently, MCSS contains information on approximately 470,000 newly diagnosed cancers in Minnesota residents.

The statute authorizing and enabling the conduct of MCSS also provided for developing Administrative Rules for the conduct of the system. Rules (short for Administrative Rules) are very important as they spell out the many definitions of terms and actions, requirements, responsibilities, and duties of the state and medical providers in Minnesota. Once formally promulgated, rules carry the same authority as statutory law. The original rules for MCSS were promulgated in 1988 as Minnesota Rules (M.R.) Chapter 4606.

The MCSS of today is very different than the MCSS of 1988. Originally, MCSS was developed as a cancer indexing system. Only those data required to describe the incidence of cancer and to facilitate research studies of cancer occurrence were collected. Primary site, histology, laterality, behavior, date of diagnosis, gender, age at diagnosis, personal identifying information, and medical providers were the major components of the base data. In the last 20 years, MCSS has become the foundation of statewide cancer control. To support this expanded mission, MCSS expanded the information obtained beyond that required for surveillance. With financial support from the National Program of Cancer Registries, information on treatment and stage have been added to the data collected on newly diagnosed cancers in Minnesota residents.

In order to keep the rules consistent with the needs, practice, and operations of MCSS, it is time to again modify MCSS Rules. The last modification occurred in 1997 to add requirements for entities to report available information on cancer stage and first course of cancer-directed treatment, and patients' race. Procedures for modifications of existing rules are defined in statute, and the process is monitored by the Department of Administration. A short preview on this process is useful to understand the steps that revising MCSS Rules will entail.

The entire process of changing administrative rules takes at least four months (usually closer to 8 months) from the time the "Request for Comments" appears in the State Register. During the Request for Comments period, the agency solicits feedback on the possible rules. Sometimes a work group is convened to iron out the details of the rule language. Based on the feedback

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obtained during the comment period, the agency develops final rule language and writes a “Statement of Need and Reasonableness,” or SONAR – a very important document. When the final language and SONAR are ready, the Minnesota Office of the Revisor of Statutes reviews and edits the language to ensure that it is clear; the Governor’s office must approve the rule; an “additional notice plan” is submitted to an Administrative Law Judge (ALJ) for approval; and if a public hearing is a possibility, then the Office of Administrative Hearings is contacted to set up a tentative date and time for the possible hearing. Next, an official “Notice of Intent to Adopt Rules” is published, and the agency sends a copy to those in its additional notice plan. Comments received during the minimum 30-day period after the Notice of Intent is published are made part of the rulemaking record. If 25 or more individuals request a public hearing, then a public hearing is held before an ALJ. With or without a hearing, the ALJ reviews all the information provided and makes a ruling, which could be to adopt as recommended, not to adopt the rules at all, or to recommend some changes prior to adopting the rules. The agency then decides what to do with the ruling. Assuming the ruling would be to adopt the rules, then the final rule is again sent to the Revisor’s office; the Governor’s office is notified; if the Governor does not veto the final rule, the Commissioner signs the “Order to Adopt Rules;” and an official “Notice of Adoption” is published in the State Register. The rule takes effect upon the date stated in the State Register notice.

The issues involved in the current MCSS Rules modification fall into two categories: five technical changes, and a proposal by the legislature to require providers to collect and report lifetime occupational and residential histories on all cancer patients in Minnesota. The technical modifications of MCSS Rules comprise (1) Change the definition of “cancer” to include those without microscopic confirmations (i.e., “when a recognized medical practitioner says the patient has a cancer or carcinoma”); (2) Modify the procedure for notifying reporting entities of changes in which data items are required; (3) Require reporting of available follow-up information; (4) Specify additional conditions under which cancer survivors can be contacted without physician consent, so that longer-term cancer survivors can be invited to participate in relevant research projects; and (5) Clarify that no *in situ* tumors of the uterine cervix are reportable. For more information on how MCSS is thinking of implementing these changes, please see the Q&A document posted on MCSS web site: [Q and A document on MCSS web site](#)¹. MCSS Advisory Committee reviewed the technical requirements at an in-person meeting held in March; they recommended that the technical amendments proceed as proposed.

During the 2007 legislative session, there was significant activity focused on requiring MCSS to collect data on occupational and residential histories on all cancer patients in the state. A bill to require this action was heard in the House of Representatives Housing Policy and Finance and Public Health Finance Committee (HF 1842). MDH spoke against the bill at the committee meeting and the bill was not approved. However, language was included in the Omnibus Health and Human Services Finance bill during Conference Committee deliberations (Chapter 147, Art. 19, Sec. 4, Subd. 6) that was signed into law on May 25, 2007. The law required MCSS to communicate with providers to include occupational and residential histories in their reporting to the MCSS.

The MCSS complied with this requirement in Volume 20 No. 2 Summer 2007 edition of the *MCSS Notes* with the notification reprinted below:

2007 Legislation that Affects MCSS

Although it affects primarily acute disease surveillance, the Omnibus Health and Human Services Finance bill (Laws of Minnesota, Chapter 147, Art. 19, Sec. 4, Subd. 6, signed May 25, 2007) contained language (in italics, below) that affects MCSS:

Disease Surveillance. Of the state government special revenue fund appropriation, \$2,000,000 the first year is for redesigning and implementing coordinated and modern disease surveillance systems for the department, and for modifying the Minnesota Cancer Surveillance database and communicating with providers to include occupational and residential histories. This is a onetime appropriation.

MCSS received a portion of the appropriation and is planning the database modifications. When we have completed the database modifications, MCSS Notes will include an article that specifies a method for reporting any available information on occupational and residential histories. The standards in statute and rules for reporting data to MCSS have not been changed.

During the summer and fall, interaction with the author of the legislation led to an agreement to convene an MCSS Rules Work

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¹ <http://www.health.state.mn.us/divs/hpcd/cdee/mcss/documents/rulechangeqanda03122008.pdf>



The Minnesota Cancer Surveillance System (MCSS)

is the state's cancer registry. It is an ongoing program within the Section of Chronic Disease and Environmental Epidemiology at the Minnesota Department of Health (MDH).

UPCOMING NAACCR HOSPITAL REGISTRY WEBINARS

Data Quality & Data Use 5/8/2008

This 4-hour class will present ways to evaluate the quality of registry data and ways to use the data.

Abstracting Upper Gastrointestinal Tract Cancer Incidence & Treatment Data 7/10/2008

This 4-hour class will include an overview of the anatomy of the upper gastrointestinal (GI) tract as needed to abstract and code upper GI cancer cases.

Abstracting Other Digestive System Cancer Incidence & Treatment Data 9/11/2008

This 4-hour class will include an overview of the anatomy of other parts of the digestive system as needed to abstract and code other digestive system cancer cases.

All Webinars begin at 8AM, and are held at Snelling Office Park, 1645 Energy Park Drive, St. Paul, MN

MCSS Notes

MCSS Notes is published quarterly by the Minnesota Department of Health, Minnesota Cancer Surveillance System (MCSS), in cooperation with the Minnesota Society of Pathologists (MSP).

Upon request, this information will be made available in alternate format, such as large print, Braille, or cassette.

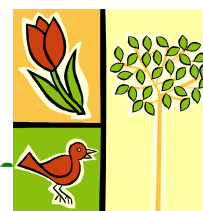
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Group to provide input and recommendations about the value of this information and how it should be collected. This portion of the MCSS Rules modification is considered controversial because significant issues of scientific validity, cost, ethical concerns, and standards of practice have been raised by the MCSS Advisory Committee and others.

This portion of the proposed rule change impacts many sectors of our population and many scientific, medical, public health, and government activities. The MCSS Rules Work Group will contain a broad representation from various stakeholders. Representatives of the following have been invited to participate: Minnesota Medical Association, Medical Ethics, Mayo Clinic, Minnesota Council of Health Plans, Cancer Alliance, Medical Clinic Administrators, Minnesota Hospital Association, Public Health Attorneys, Organized Labor, Industry, University of Minnesota Cancer Center, Minnesota Pollution Control Agency, University of Minnesota School of Public Health, Minnesota Department of Labor and Industry, Minnesota Cancer Registrars, Minnesota Nursing Association, Data Privacy advocates, University of Minnesota Epidemiology, Non Minnesota Centralized Cancer Registry, Environmental Advocates, and Legislators. The members of the group are expected to have differing opinions on this proposal, and the Minnesota Department of Health will consider all points of view when the rule amendments are developed.

It is expected that the rule making process will be completed by the end of this year. If you have any questions or concerns about the proposed rules, you are encouraged to contact Dr. Sally Bushhouse, MCSS Director, by e-mail at Sally.Bushhouse @ state.mn.us.