



## FACT SHEET

# From the Missouri Cancer Registry (MCR) Frequently Asked Questions

### Long-term Care Facility Cancer Reporting

**Where can I find Missouri's cancer reporting statute and the rule that governs reporting?**

The statute, 192.650-192.657 RSMo, can be found in the Long-Term Care Facility Cancer Reporting Manual, as well as on the state web site at <http://www.moga.state.mo.us/homestat.asp>. The rule, 19 CSR 70-21.010 can be found at <http://www.sos.state.mo.us/adrules/csr/csr.asp> (Title 19, Division 60).

**Why does the new law include long-term care facilities?**

In 1984, when the State of Missouri first required reporting of cancer, almost all cancer cases were diagnosed and treated in a hospital setting. Due to changes in the healthcare delivery system, an increasing number of cancer cases are now being treated outside the hospital setting. In 1999 in an effort to decrease underreporting, the law was changed to include a variety of non-hospital health care facilities, including pathology laboratories, ambulatory surgery centers, freestanding cancer clinics and physician offices as well as long-term care facilities (LTCFs).

**Can't you get enough information from hospitals?**

To accurately determine the incidence of cancer in Missouri residents, we need to have between 95% and 100% of all cancer cases diagnosed in a given year reported to the Missouri Cancer Registry (MCR). The only way to obtain that high a percentage of cases is to have a variety of reporting sources. That way, if a patient is not in a hospital registry, MCR will be able to identify the patient through one of the other reporting sources. In addition to obtaining information from Missouri facilities, MCR has case-sharing agreements with central registries in all bordering states and a number of other states where Missouri residents are likely to be diagnosed and/or treated (e.g., Arizona, Florida, Texas, etc.).

**Is it realistic to include residential and intermediate care facilities?**

The law does not differentiate between skilled nursing facilities (SNFs), intermediate care facilities and residential care facilities. Therefore, MCR must include all facilities. In reality, we anticipate that the majority of LTCF cancer cases will be residents of SNFs. This is supported by a review of 1999 death certificate cases whereby we learned that 85% of the patients who died while residing in a LTCF were SNF residents. (See below for a more detailed explanation of the death certificate process, also called death clearance and follow back.)

**Who should be doing the reporting?**

From our perspective, any one of several staff members may complete the reporting form. One suggestion is the Minimum Data Set (MDS) coordinator because that person will already be familiar with the patient's chart and health history. Other possibilities might be the director of nursing or a staff member who is familiar with disease reporting to the Missouri Department of Health and Senior Services (DHSS).

**What does MDS have to do with cancer reporting?**

MCR sought to identify existing networks involved with LTCFs and found that Dr. Marilyn Rantz's QIPMO program offered a framework for distributing information, conducting training and providing ongoing communication to SNFs.

**When do I send in the information?**

According to the law, the information is to be sent in at least quarterly. If it is more convenient, you may send in forms as they are completed.

**Will reporting be manual or electronic?**

Initially, reporting will be manual. Optional electronic reporting is our goal.

**What if I can't find all the information requested on MCR's reporting form?**

It may not always be possible to provide complete details relating to a patient's cancer diagnosis. Diagnosis date and primary site are absolutely necessary. Other details are important but may not be readily available to nursing home staff. In those cases, LTCFs can provide names of institutions/physicians who can be contacted for further information. (Physicians' offices will probably decline to release cancer details to LTCFs because of HIPAA regulations.)

## Frequently Asked Questions (continued)

If the LTCF staff member completing MCR's reporting form is uncertain about what to include on MCR's reporting form, pertinent portions of a patient's chart can be submitted for our review (e.g., history and physical, operative summary, pathology report).

### **Should I call the patient's family for details that I can't find in the facility's medical record?**

That is not necessary. We appreciate your willingness to do this, but as long as you have provided us with referral information, we should be able to follow-back to the physician and/or hospital for additional data.

### **Does MCR offer training?**

MCR originally offered through MDS support groups. More recently, MCR has gone to annual regional training sessions. Our plans also include creating computer and/or web-based training.

### **What about patients in private beds? Do I have to report them?**

Yes. The law includes all patients in all types of LTCFs.

### **May I report all patients who have cancer?**

Yes. It may be easier and save time to report all patients with cancer or a history of cancer, rather than determining which ones to report. MCR will determine which patient information is needed for the database.

### **What is the death certificate process?**

The death certificate process, also referred to as "death clearance and follow back" involves matching individuals whose death certificate lists cancer as a cause of death (immediate or underlying) to the patient records in the MCR database. MCR follows up on any patient not matched with a record in the MCR database by contacting the facility listed on the death certificate. The death clearance process for individuals who died in 2001 is tentatively scheduled to begin in June 2003.

### **Why do you wait so long to ask for death information?**

Hospital cancer registries abstract data on a delayed basis because complete treatment information is usually not available until four to six months after diagnosis. Hospitals then submit electronically reported data or paper abstracts to the central registry, where the data is reviewed for completeness, accuracy, etc. This process takes several months. MCR obtains names of individuals who died from cancer in the same year from DHSS's Bureau of Vital Statistics. By this time, it may be 18 – 24 months after the patient expired at your facility.

### **Do I have to wait until MCR requests death information for a patient?**

When a patient dies at your facility and the patient either has cancer or a history of cancer, you may voluntarily report that patient to MCR. The primary cause of death may or may not be related to the cancer diagnosis. Remember, we review these patients based on the information as it is coded on the death certificate. You do not have to wait for MCR to ask for the death information. In fact, this should work to your advantage, and possibly eliminate any delayed requests from MCR.

### **How do I know what information is on the death certificate? The physician takes care of that.**

Some facilities require a copy of the death certificate for the patient's chart. For other facilities, it may be more difficult to know which patients to report. This is an issue that each facility may want to address if it is interested in voluntarily reporting deaths as they occur.

### **What if I have suggestions that will improve the cancer reporting form or the policies and procedures?**

Please send us your comments and suggestions. We welcome any input that may improve the reporting process.

### **How do I contact MCR?**

Please feel free to call Nancy Cole, Non-Hospital Coordinator with any questions you have about information contained in this letter. Ms. Cole can be reached toll-free at 866-240-8809 or by e-mail ([colen@health.Missouri.edu](mailto:colen@health.Missouri.edu)).