

MISSOURI CANCER REGISTRY Patient Information



What is the Missouri Cancer Registry?

In 1984, state law established the Missouri Cancer Registry (MCR) to collect and analyze data about new cases of cancer diagnosed in Missouri hospitals. Due to changes in health care delivery, the laws were expanded in 1999 (192.650 – 192.657 RSMo) to include various non-hospital facilities including ambulatory surgery centers, free-standing cancer treatment centers, pathology laboratories, nursing homes and in some cases, physicians. All other states in the U.S. have similar cancer registries. Also in 1999, the MCR became part of a collaborative partnership between the Missouri Department of Health & Senior Services (DHSS) and the Center for Health Care Quality, University of Missouri – Columbia.

What is the purpose of the Missouri Cancer Registry?

The MCR has several purposes:

- ❖ To collect the data used to monitor and assess overall cancer incidence and trends in the state, which in turn may be used by public health professionals for program development and evaluation
- To provide information for community assessment of environmental and occupational hazards, and
- ❖ To provide data for cancer research and epidemiological studies.

How and what information is collected?

The MCR currently collects information from several sources: all acute care hospitals in Missouri, pathology laboratories, nursing homes, ambulatory surgery centers, free-standing radiation and/or chemotherapy clinics and, in some cases, physicians. The MCR also has agreements with other state central cancer registries to obtain information on Missouri residents who are diagnosed with or receive treatment for cancer in these states. MCR processes 36-40,000 records annually, including information on over 28,000 new Missouri cases.

The MCR collects two main types of information on its reporting forms:

- Information about the person diagnosed with cancer (e.g., age, sex, race, place of residence and occupation), and
- ❖ Information on the cancer diagnosed (e.g., type of cancer, date of diagnosis and stage at which the cancer was diagnosed).

How is this information kept confidential?

The MCR adheres to strict confidentiality protections. Only aggregate data (data that gives overall numbers, such as the number of people in a county diagnosed with lung cancer during a time period, or the number of women statewide diagnosed with breast cancer) are published.

Case-specific data are confidential by law, and are released only to approved medical and epidemiological researchers after a thorough review of research requests that includes Institutional Review Board (IRB) approval. Any approved researcher given access to such data is required both by law and by contract with DHSS to keep that information strictly confidential.

Further information about cancer reporting and links to other websites may be found on the MCR website: http://mcr.umh.edu. For Missouri statistics, go to http://www.health.state.mo.us/CancerMICA/.

The Missouri Cancer Registry is certified by the North American Association of Central Cancer Registries (NAACCR).