THE MISSOURI CANCER REGISTRY

The Missouri Cancer Registry (MCR), established in 1972, serves as a statewide cancer database. Cancer reporting for Missouri hospitals was voluntary until 1984 when the Missouri General Assembly passed a bill to require cancer reporting of inpatient cancer cases. Consequently, 1985 represents the first year that Missouri cancer incidence rates can be calculated.

Responding to public health needs, Congress established the National Program of Cancer Registries (NPCR) in 1992. Administered by the Centers for Disease Control (CDC), this program provides funds to enhance or establish state central cancer registries. Missouri became a NPCR state in 1996.

In 1999, the late Governor Mel Carnahan signed an expanded cancer reporting law. This law required that pathology laboratories, ambulatory surgery centers, freestanding cancer clinics and treatment centers, physicians and nursing homes report cancer cases.

WHAT IS A CANCER REGISTRY?

A cancer registry is a system for the collection, storage, analysis and the interpretation of data on cancer patients. Cancer registries may be hospital-based or centralized.

Hospital-based cancer registries use information obtained from medical records to assess the exact number of diagnoses per year in that particular hospital and the relative frequencies of cancers by site.

Central cancer registries, such as MCR, depend on the information obtained from the hospital-based registries as well as other reporting facilities. The data are then accumulated at the central registries to make statistically significant analyses of cancer incidence and prevalence possible.

WHAT IS REPORTED?

- Patient demographics (age, gender, race, Spanish origin, place of birth and residence)
- Primary site of cancer
- Tumor histology
- Stage or extent of disease
- Treatment performed or initiated (surgery, radiation, chemotherapy, hormone or immunotherapy)
- Current status of patient

WHAT IS A CANCER REGISTRAR?

According to the National Cancer Registrars Association (NCRA), an organization of cancer registration and surveillance professionals, cancer registrars are data management experts who report cancer statistics for various healthcare agencies. The primary responsibility of the cancer registrar is to ensure that timely, accurate, and complete data is gathered and maintained on all types of cancer diagnosed and/or treated within an institution or other defined population.

WHAT DOES MCR PROVIDE FOR MISSOURI?

* Data for determining the incidence and prevalence of cancer
* Data necessary to analyze possible cancer clusters
* Data analysis of cancer incidence trends by geographical area, race, gender, primary site, etc.
* Data for research and epidemiological studies
* Data for planning and evaluating public health initiatives

WHAT ABOUT CONFIDENTIALITY?

Based on the HIPAA privacy regulations, MCR is a “public health authority” authorized by law to collect and receive such information for the purpose of preventing and controlling disease, injury or disability, including…reporting of disease…and the conduct of public health surveillance….” [C.F.R. 164.512 (b)(1)(i) (2001)] Therefore, a covered entity (i.e. hospital) may continue to disclose protected health information without specific individual informed consent.

Non-confidential summary statistics will be released in annual reports or upon request, but the identity of the patient, hospital, physician, health care provider, pathology laboratory, ambulatory surgical center, free-standing cancer clinic or treatment center will not be released without written consent from the concerned individual or facility.

WHO CAN REQUEST DATA?

For information about obtaining aggregate data call MCR at 1-800-392-2829. These data are available to citizens of Missouri, students, healthcare professionals, researchers and others. A fee may be charged. Strict confidentiality is maintained. Patient or reporting facility identifiers are not released without written permission.

MCR ADVISORY BOARD

The Missouri Cancer Registry has established an advisory board of physicians, cancer registrars from various institutions, hospital administrators, an epidemiologist, and Missouri Department of Health employees. The advisory board has helped MCR to receive support and assistance from hospitals and health professionals statewide. The advisory board, in addition to the other services provided by MCR, has helped the registry to develop a strong relationship with officials throughout the state.

PARTNERSHIPS
In 1999, the Missouri Department of Health contracted with the Center for Health Care Quality at the University of Missouri to house, and collaborate with MCR and the Behavior Risk Factor Surveillance System (BRFSS). This partnership with the University has made possible expanded capabilities and increased opportunities for involvement in research.

STAFF

The MCR boasts a well-trained and experienced staff that includes Certified Tumor Registrars with hospital-based registry experience. Staff members are encouraged to attend state, regional and national meetings to maintain an acceptable level of expertise.

TRAINING

For hospitals: MCR provides on-site one-on-one training for new registrars and presents Basic Cancer Registry Training and other educational workshops. For more information, please call 1-800-392-2829 (573-882-7775).

For non-hospital healthcare facilities: MCR will be offering training for non-hospital personnel who will be assisting in the reporting of cancer cases. For more information, please call 1-866-240-8809 (573-884-2491).

Correspondence may be directed to:
Missouri Cancer Registry
PO Box 718
Columbia Missouri 65205-07981
Fax: 573-884-9655

“Now that we have the medical knowledge that can bring good health within our reach to a degree heretofore undreamed of, we must improve the means for putting that knowledge to practical use.”
--Harry S Truman, April 22, 1949.