

## STATE REGISTRIES

The Human Services Committee at its January 7, 2014, meeting asked the Legislative Council staff to identify information regarding state registries established in North Dakota which are similar to a brain injury registry. A summary of the registry information identified is listed below.

### STATE TRAUMA REGISTRY

North Dakota Century Code Section 23-01.2-01 states the Health Council, in conjunction with the State Department of Health, may establish and maintain a comprehensive trauma system for the state. North Dakota Administrative Code Section 33-38-01-08 requires that all hospitals submit data to the state trauma registry specific to trauma patients that present to their emergency rooms. The state trauma registry is maintained by the State Department of Health. Each facility has a trauma coordinator responsible to submit data to the trauma registry. The coordinator is also responsible to monitor the facility's compliance with trauma quality standards both at the hospital and prehospital level by using this data. Data from the trauma registry is reviewed on a quarterly basis by the state and regional trauma committees. Specific cases are reviewed through a performance improvement process to improve patient outcomes, reduce the severity of injuries, and identify system issues as they occur. Data from the registry is requested by various agencies and researchers involved in injury surveillance. Data from the registry is also used to generate reports which are used by facilities for benchmarking.

### EMERGENCY MEDICAL SERVICES PATIENT CARE REGISTRY

The emergency medical services (EMS) patient care registry is maintained by the State Department of Health. Data is entered into the registry by individual care providers and aggregated by the vendor. Each hospital in North Dakota has the ability to access the patient's information from the EMS agency through the state registry. The registry is used to evaluate the EMS system in North Dakota and to monitor response time standards. The data is linked with the Department of Transportation's fatal accident reporting system to provide response times in fatal crashes. Data from the registry is requested by various agencies and researchers looking at injury and chronic disease surveillance.

### STATE STROKE REGISTRY

Hospitals submit data specific to stroke patients that present to their emergency rooms to the state stroke registry, which is maintained by the State Department of Health. Facilities have an individual responsible to submit data to the registry. This person is also responsible to monitor the facility's compliance with quality standards both at the hospital and prehospital level by using this data. The intent is that specific cases from this registry will be reviewed through a performance improvement process to assure compliance with standards of care, improve patient outcomes, and identify system issues as they occur. Data from the registry may be requested by various agencies and researchers involved in stroke-related data and used by facilities for benchmarking.

### ST-ELEVATION MYOCARDIAL INFARCTION REGISTRY

North Dakota Century Code Section 23-47-02 requires the State Department of Health to establish and maintain a comprehensive emergency cardiovascular medical system for the state. Hospitals submit data specific to patients that present to their emergency rooms with ST-elevation myocardial infarction (STEMI)--a type of heart attack--to the STEMI registry. Facilities have an individual responsible to submit data to the registry. The individual is also responsible to monitor the facility's compliance with quality standards both at the hospital and prehospital level by using this data. The intent is that specific cases from this registry will be reviewed through a performance improvement process to assure compliance with standards of care, improve patient outcomes, and identify system issues as they occur. Data from the registry may be requested by various agencies and researchers involved in cardiac systems of care-related data and used by facilities for benchmarking.

### REPORTABLE DISEASES OR CONDITIONS REGISTRY

North Dakota Century Code Section 23-07-01 requires the State Department of Health to designate diseases that must be reported. The reportable disease registry is used to monitor trends for infectious or communicable conditions of public health significance. For several diseases, epidemiological information is captured and entered into the registry. For other diseases, only basic demographics are captured.

### AUTISM SPECTRUM DISORDER DATABASE

The purpose of the autism spectrum disorder database established by 2013 House Bill No. 1038 is to ensure there is a record of all reported cases of autism spectrum disorder in the state and any other information determined relevant and appropriate to the State Department of Health in order to complete epidemiologic

surveys of autism spectrum disorder, enable research and analysis of autism spectrum disorder, and provide services to individuals with autism spectrum disorder.

### **NEWBORN SCREENING DATABASE (METABOLIC AND GENETIC REGISTRY)**

North Dakota Century Code Section 25-17-03 requires the State Department of Health to maintain a registry of cases of metabolic and genetic diseases. The newborn screening database contains information for the North Dakota, South Dakota, and Iowa newborn screening programs and is also referred to as the "Iowa" database or the neonatal metabolic screening program database. The newborn screening database is accessible online through the State Hygienic Laboratory at the University of Iowa website. The newborn screening database contains patient information, demographics, and limited case information for each newborn born in North Dakota that received a bloodspot screening. Each client record contains laboratory results, documentation of short-term followup activities conducted by nurses and medical consultants, outcomes, and referral information. Newborns are followed by the newborn screening program in this database until a diagnosis is confirmed or ruled out. The newborn screening program also utilizes this database to review cases and determine quality improvement activities.

When notified, Children's Special Health Services staff provides additional care coordination support to families that have infants with positive screens to link them to needed services. When authorized by the family, Children's Special Health Services staff also provides a history of laboratory results obtained from the newborn screening database to the metabolic disorders clinic team. The team uses the laboratory results to develop treatment plans for the individuals that attend a multidisciplinary clinic. Multidisciplinary teams are considered "best practice" and support coordinated management of complex chronic health conditions.

### **NORTH DAKOTA BIRTH DEFECTS MONITORING SYSTEM**

The North Dakota birth defects monitoring system is maintained by the State Department of Health. The purpose of the birth defects monitoring system is surveillance of birth defects in North Dakota. This includes annual reporting of prevalence or incidence rates based on a five-year term of birth defects in North Dakota for 43 major congenital anomalies. Efforts are also directed for the education of the general public and health professionals about the causes, surveillance, impact, and prevention of birth defects.

Active case determination and confirmation is not conducted. Surveillance is conducted through a passive system, which utilizes data collected from four secondary data sources:

- North Dakota vital statistics (birth certificate or death certificate).
- Children's Special Health Services client server application and database.
- Department of Human Services Medical Services Division claims system.
- University of North Dakota (UND) School of Medicine and Health Sciences Division of Medical Genetics.

### **STATEWIDE CANCER REGISTRY**

North Dakota Century Code Section 23-07-01 requires the State Department of Health to maintain a uniform statewide population-based registry system for the collection of data pertaining to the incidence, prevalence, risk factors, management, survival, mortality, and geographic distribution of cancer and reportable benign tumors. The statewide cancer registry collects information about new cancer cases, cancer treatments, and cancer deaths. All hospitals, laboratories, physicians, and other health care providers are required by state law to report all newly diagnosed or treated cancer patients. This data is collected and kept in the registry's secure and confidential database. Data is used to monitor cancer trends, promote research, increase survival, guide public health planning, and respond to cancer concerns and for evaluation. The statewide cancer registry can be used to monitor cancer incidence patterns in North Dakota by providing summary statistics on the distribution of cancer cases by type and the following of cancer incidence and treatment trends throughout the state. In 1994 the State Department of Health began receiving funding from the federal Centers for Disease Control and Prevention's National Program of Central Cancer Registries under the federal Cancer Registries Amendment Act. These funds allowed for the establishment of the statewide cancer registry for the purpose of timely, accurate, and complete data collection. In 1996 the State Department of Health administrative rules were amended to include cancer as a reportable condition. This amendment mandates all facilities diagnosing or treating cancer to report the data to the statewide cancer registry. The statewide cancer registry has been collecting information about patients diagnosed with cancer since January 1997. In July 2012 the UND School of Medicine and Health Sciences Department of Pathology became the State Department of Health's bona fide agent to operate the statewide cancer registry; however, the State Department of Health retains ownership of all data.