

# Inventory of Biological Specimens, Registries, and Health Data and Databases

REPORT TO THE LEGISLATURE

MARCH 2017

## **Inventory of Biological Specimens, Registries, and Health Data and Databases**

February 2017

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*As requested by Minnesota Statute 3.197: This report cost approximately \$5,500 to prepare in 2014, including staff time, printing and mailing expenses, and required minimal effort to update for 2016 changes.*

*Upon request, this material will be made available in an alternative format such as large print, Braille or audio recording. Printed on recycled paper.*

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# Introduction:

The Minnesota Department of Health is charged by statute with collecting, managing, storing, using and disseminating a wide variety of data that is used to characterize the health and health risks of Minnesotans. Some of that data comes from the health care community, some from other agencies, and some from individuals directly. In all cases, information that is individually identifying must be managed according to the Minnesota Data Practices Act to protect the privacy of the individual with rare exceptions in which the Commissioner can share data needed to protect the health of the public. Even in those rare exceptions, the Commissioner is charged with sharing as little as possible with as few people as possible, and only to control or prevent the spread of serious disease (*Minn. Stat. §13.3805 subd.1(b)*).

The following list of biological specimens, registries, and health data and databases describes the types of data and materials analyzed by the Department and used to notify an individual of their exposure to a disease, condition, or environmental exposure; to confirm or contain a disease outbreak; to study the spread, risk factors, or evaluate prevention or control measures for a particular disease, condition, or exposure; and to identify new and emerging conditions. Accurate, timely and complete data that can be compared with previous time periods can be critical to a deeper understanding of the preventable or controllable health risks that exist in Minnesota today.

This report includes the information requested by the Legislature under Minnesota Statutes, section 144.193, as well as the Minnesota Statute or Rule authority or federal law that authorizes the collection, use and storage of the data used by the Department's programs. The report provides a brief description of the type of data or specimen collected and the purpose for the collection. Additional information about the biological specimens, registries, health data and databases is available upon request. Please contact the Commissioner's Office at the Minnesota Department of Health.

# Definitions:

**Biological Specimens:** Tissue, fluids, excretions, or secretions that contain human DNA originating from an identifiable individual, either living or deceased. Biological specimen does not include infectious agents or chemicals that are isolated from a specimen. *Minn. Stat. § 144.192, subd.1(b)*.

**Registry:** A legal term of art used for a collection of identifying and sometimes health information about an individual used for specific purposes as defined by the authorizing statutory language. Some purposes of a registry for MDH include registering a unique type of provider e.g., Interpreter Service Registry or for development of quality improvement, injury prevention, treatment and rehabilitation programs, e.g., trauma registry.

**Health data and database:** Health data are data on individuals created, collected, received, or maintained by the Department of Health relating to the identification, description, prevention, and control of disease or as part of an epidemiologic investigation the commissioner designates as necessary to analyze, describe, or protect the public health. *Minn. Stat. § 13.3805, subd. 1(a)(2)*. Health data are managed through the use of databases. A database is a collection of information.

# Biological Specimens

Type of specimens	Purpose for use of the specimen	Length of storage for initial testing	Length of storage for program operations or public health practice
Stool, blood, respiratory secretions, tissues, non-respiratory secretions, other body fluids	Infectious disease diagnosis, public health disease monitoring and investigation, special public health projects	Until diagnostic testing is complete (2 days to 6 weeks)	Retain until testing is completed then destroy.
Stool, blood, respiratory secretions, tissues, non-respiratory secretions, other body fluids	Outbreak investigation	6 months beyond completion of testing or investigation is completed	Retain for 10 years then destroy.
Stool, blood, respiratory secretions, tissues, non-respiratory secretions, other body fluids	Special public health projects to monitor infectious disease trends and Biomonitoring projects for environmental exposures	Defined by the individual project or investigation	Retain as defined by individual project, or until the project is completed then destroy.
Stool, blood, respiratory secretions, tissues, non-respiratory secretions, other body fluids	Public health research (as defined in the Code of Federal Regulations covering individual research)	Defined by the individual project or investigation or as limited by the person's informed consent	Retain as defined by individual project, or until the project is completed then destroy.
Blood spots	Newborn screening	Varies; 30 day minimum	Permanent for specimens collected on or after August 1, 2014.

# Programs defined as a registry by Minnesota Statutes

Registry name	Statute and rule reference	Type of data collected	Purpose of registry	When started	Length of storage
Medical Cannabis Registry	MS 152.27; 152.31	Information on persons with qualifying medical conditions, providers, and caregivers.	Evaluate data on benefits, risk and outcomes in therapeutic use of medical cannabis	2015	Permanent
Interpreter Services Registry	MS 144.058	Name, qualifications, contact information, languages spoken	Provide for voluntary registration of spoken language health care interpreters used by healthcare providers	2008	Current registrants only (annual renewal required)
Certified Doula Registry	MS 148.996	Contact information, certification status, criminal background check information	Provide contact information about persons trained to provide emotional and physical support during pregnancy, labor, birth and postpartum	2007	Current registrants only (renewal required every three years)
Trauma Registry	MS 144.6071	Demographic information on people who sustain major trauma, plus type of injury, treatment and outcome.	Evaluate the effectiveness of the trauma system in saving lives and designate trauma hospitals and improve the trauma system.	2005	Permanent
Minnesota Father's Adoption Registry	MS 259.21; 259.49; 259.52	Information about putative (assumed) fathers, mother and child	Preserve and maintain identification and location data for assumed fathers, in order to facilitate notice about adoptions	1998	20 years
Traumatic Brain Injury and Spinal Cord Injury Registry	MS 144.661-144.665; MN Rules Chapter 4563	Information about hospitalized persons with brain or spinal cord injury	Develop programs and improve outcomes by providing information about resources to injured persons.	1993	Permanent

Nursing Assistant Registry	MS 144A.61	Contact information, training information, information about misconduct	Provide list of qualified nursing assistants who work in long-term care facilities for use by employers	1989	Permanent
Cases of Heritable and Congenital Disorders Detected by the Newborn Screening Program	MS 144.125-144.128; MN Rules Parts 4615.0300 to 4615.0760	Information on children diagnosed with a disorder found through Newborn Screening	Provide parents with support and information for follow-up services	1985	18 years

# Health Data and Databases

Health data and databases	Statute and rule reference	Type of data collected	Purpose of program	When started	Length of storage
Biomonitoring Studies	MS 144.995, 144.996, 144.997, 144.998	Information about an individual's exposures through questionnaire and laboratory testing in special studies for chemicals in body fluids (informed consent required)	Measure levels of certain chemicals and how levels change over time	2007	Permanent
Newborn Hearing Screening	MS 144.966	Test results and information about babies screened for hearing problems	Find newborns with hearing disorders requiring treatment and/or follow-up	2007	18 years
Birth Defects	MS 144.2215-144.2219	Information on children with birth defects and treatment effectiveness	Provide information about occurrence and risk factors for birth defects; offer services to affected	2004	Permanent; unless opt out
Minnesota Immunization Information Connection	MS 144.05, 144.3351	Information on individuals about vaccines received and contraindications	Identify gaps in immunizations and assist providers in knowing vaccine status and providing reminder notices	2002	Permanent

Pregnancy Risk Assessment Monitoring System	MS 144.05	Information from mothers that have a live birth collected between 2 and 6 months post-partum	Identify and monitor selected maternal experiences and behaviors that occur before and during pregnancy and during the child's early infancy to design programs to increase positive outcomes	2002	Permanent with informed consent
Blood Lead Surveillance System	MS 144.9501-144.9512	Information on individuals with blood tests	Monitor testing activities and track elevated blood lead cases in the state to provide the basis for intervention	1995	Permanent
Hepatitis B Maternal Carrier Data	MS 144.3352 MN Rules Part 4605.7044	Information on women who are carriers of Hepatitis B	Identify infected mothers so their newborns can be treated right after birth to prevent disease in the infant	1994	5 years
Infected Healthcare Worker	MS 214.17-214.25	Information on licensed health care workers infected with HIV, HBV, and HCV	Determine practice restrictions and monitor compliance	1992	Retain for 6 years after case closed.
Minnesota Cancer Surveillance System	MS 144.671 – 144.69 and MN Rules Chapter 4606	Information on persons with malignant and in situ tumors diagnosed in MN	Monitor the occurrence of cancer and describe risks of developing cancer, inform about cancer risks, answer concerns about cancer, promote cancer research and guide decisions about cancer control resources	1988	Permanent

Site Assessment and Consultation Health Studies	MS 144.05	Records of environmental exposure investigations. Each investigation has a separate data set	Develop public health action plans for affected communities and individuals	1987	Permanent
Sage Cancer Screening Program	MS 144.05, 13.3805 and federal grant	Information on program participants screening results, referrals, treatment, treatment outcomes	Provide cancer screening to low income and underinsured women. Assure women with positive screening results are referred for treatment	1985	Permanent
Refugee health Screening and Case Management	Federal Refugee Act of 1980	Information about persons received in Minnesota through the Refugee Resettlement Program	Assess population and health trends and assist with accessing care and case management	1980	Permanent
Tuberculosis Medication Dispensing	MS 144.05; 151.37; MN Rules Chapter 4605	Treatment information on persons with TB disease	Document prescription information, eligibility, communication with the dispensing pharmacy and verification that drugs were dispensed	1980	A one-page summary is retained but supporting documentation destroyed upon case closure.
Women's Infants and Children (WIC) Nutrition Program	Federal Healthy Hunger Free Kids Act	Information on participants who are eligible for WIC services	Provides nutrition and breastfeeding services, healthy foods and referrals to low-income women and young children	1972	6 years after the date of the last participant activity.
Newborn Screening Program (except hearing)	MS 144.125 to 144.128; MN Rules Parts 4615.0700 and 4615.0750 to 4615.0760	Test results and information about babies screened for inherited or genetic conditions	Find newborns with disorders requiring immediate treatment	1965	Permanent for data collected on or after August 1, 2014.

Food, Pools and Lodging Services	MS 31.101; 31.11; 144.05; 144.12; 144.122; 157.011; MN Rules Chapter 4626 and 4717	Non-illness related complaints about a food, beverage and lodging facility, manufactured home park, recreational camp ground, youth camp or public swimming pool.	Investigate food-borne or water-borne illness complaints to determine source of disease and stop further cases; monitor exposures and outbreaks	1950s	Non-illness related complaints are kept for 5 years after the complaint is closed
Investigation and Control of Occupational Diseases	MS 144.05; 144.34; 176.234	Information from short term or ongoing studies on persons or populations related to occupational injuries, diseases, or exposures to hazards	Monitor the occurrence of occupational injuries, diseases, and hazards and conduct special investigations of high-risk populations	1939	Varies between 10 years and permanent
Minnesota Children with Special Health Needs	MS 145.88	Information about individuals who received financial or clinic services	Provide diagnostic evaluation and financial assistance with specialized medical care	1936 through 2008	7 years after case closed or if person was a minor 7 years after age of majority
Death Records	MS 144.211 to 144.227; MN Rules Chapter 4601	Information about deceased individuals	Register deaths and monitor causes of death	1908	Permanent
Birth Records, Fetal Death Records	MS 144.211 to 144.227; MN Rules Chapter 4601	Information about newborns and mother, including fetal deaths	Register births and monitor health issues of newborns	1900	Permanent
Communicable Diseases	MS 144.05; MN Rules Chapter 4605	Information on persons with infectious or communicable reportable conditions	Control disease outbreaks; prevent disease; assess disease burden; assess impact of preventive measures	1880s	Permanent
Communicable Diseases-Case Management	MS 144.05; MN Rules Chapter 4605	Information on persons with infectious or communicable reportable conditions	Provide for case management of patients with TB, perinatal hepatitis B and HIV/AIDS	1880s	5 years

# Appendix: Minnesota Statutes, Section 144.193

“By February 1, 2014, and annually after that date, the commissioner shall prepare an inventory of biological specimens, registries, and health data and databases collected or maintained by the commissioner. In addition to the inventory, the commissioner shall provide the schedules for storage of health data and biological specimens. The inventories must be listed in reverse chronological order beginning with the year 2012. The commissioner shall make the inventory and schedules available on the department's Web site and submit the inventory and schedules to the chairs and ranking minority members of the committees of the legislature with jurisdiction over health policy and data practices issues.”