



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

REPORT TO THE LEGISLATURE

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

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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 2018 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 |

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| 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 |

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| 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 cased 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 |

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| 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. |

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|--|--|---|---|-------|---|
| 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 |
| 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.”