



Genetic Information Authorization

Summary

This proposal will authorize the commissioner of health to collect, use, store, and disseminate genetic information for existing activities at the Department of Health where express authorization is not already provided in law.

Background

Minnesota Statutes 13.386 requires genetic information held by government entities cannot be collected, used, stored, or disseminated without the express written consent of the individual or express authorization in law. Genetic information is defined in this statute to be both biological specimens and health data. Most health data used by MDH have a genetic component; however, many MDH statutes and rules give only general authority for MDH's activities.

In 2012, the Legislature provided MDH the authorization to collect, use, store, and disseminate genetic information to the extent required or permitted by any statute or rule until July 1, 2013. Before that date, MDH must propose legislation to authorize the collection, use, storage, and dissemination of genetic information for existing activities at the Department of Health where the Commissioner determines express authorization is not already provided in law.

Recommendation

The proposal will add a section to Minnesota Statutes – 144.192 – that provides the authorization for the

collection, use, storage, and dissemination of health and genetic information for existing MDH activities.

This new statute clarifies how health data and biological specimens are to be managed in the three areas of program operations, public health practice, and health oversight activities. It mandates the development of a storage schedule for human biological specimens and defines research to be consistent with federal common rule for the protection of human subjects.

The new statute does not change any of the provisions of the newborn screening program that were enacted by the 2012 legislature. It preserves other provisions of law that might have more specific restrictions on the collection, use, storage or dissemination of genetic information.

Some of the provisions of the new statute would extend to boards of health and community health boards in their role of collecting, using, storing, or disseminating genetic information for public health purposes.

This statute will allow MDH to continue to protect the public's health in the state of Minnesota while allowing for the continued protection of genetic information on individuals.

In a related provision, the bill extends the Newborn Hearing Screening Advisory Committee until June 30, 2019.

For more information:

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