

Legislative Commission on Data Practices
Proposed Recommendations
December 7, 2018

This report contains recommendations from the Legislative Commission on Data Practices. These recommendations are based on the commission meetings held between June 2018 and December 2018. Specifically, this report addresses the following three topics:

1. patient consent and disclosure of medical records under the Minnesota Health Records Act;
2. privacy issues regarding direct-to-consumer genetic testing; and
3. notification requirements for data security breaches at government entities.

1. Recommendations: Patient Consent and Disclosure of Medical Records under the Minnesota Health Records Act

This subject came to the Commission's attention as a result of Representative Zerwas's bill H.F. 3312, which was introduced in the 2018 legislative session. That bill would change Minnesota's Health Records Act (*see* Minn. Stat. §§ 144.291–144.298) so that its restrictions on the disclosure of patient medical records would align more closely the federal Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule (*see* 45 C.F.R. §§ 164.500–134.534). The Commission heard considerable testimony on this matter, including testimony from: proponents and opponents of the proposed change; stakeholders; Maren Bardal, Researcher for the Commission; and other experts including, Dr. Lisa Moon.

The Commission has the following recommendations:

- a. All Minnesota healthcare providers should be required to use a "Universal Patient Consent Form" to guide disclosure of a patient's medical records.*

The requirement for a universal consent form could be added to Section 144.293, subdivision 2, which currently addresses patient consent. The universal consent form should allow patients to specifically consent or refuse consent to disclosure of medical records for each of the following purposes:

- treatment;
- payment;
- health care operations;
- medical/scientific research;
- disclosure of presence; and
- participation in a record locator service or health information exchange.

The universal consent form should also contain a notice of patient rights.

- b. Providers should be prohibited from conditioning a patient's treatment on the patient's willingness to consent to disclosure of medical records.*

Providers should not be able to deny treatment to a patient based on the patient's refusal to consent to disclosure of his or her medical records.

2. Recommendations: Privacy and Direct-To-Consumer Genetic Testing

The Commission heard testimony regarding privacy concerns related to direct-to-consumer (DTC) genetic testing from the following individuals: Nathan Hopkins, of the House Research Department; Peter Pitts, President of the Center for Medicine in the Public Interest; and Kathy Hibbs, Chief Legal and Regulatory Officer of 23andMe.

The Commission has the following recommendations:

- a. "Informed consent" should be defined for purposes of Minnesota Statutes, section 13.386.*
- b. Define more specifically "genetic information" in section 13.386, and add language that protects de-identified genetic information.*
- c. Add civil penalties and/or a private right of action for nongovernmental entities that violate section 13.386.*
- d. Consider further research into Alaska's Genetic Privacy Act.*
- e. Address specific privacy concerns outlined on page 3 of the November 15, 2018, House Research Department memorandum to the Commission.*
- f. Clarify who owns and controls an individual's genetic information.*
- g. Require DTC genetic testing companies to disclose their privacy policies to potential customers and get a customer's informed consent to the privacy policy before the customer purchases a DNA testing kit.*
- h. Require DTC genetic testing companies to disclose to customers the identity of all entities who will have access to the customer's genetic information or other personal information.*
- i. Consider requiring DTC genetic testing companies to perform periodic independent audits to prove the proper handling of customers' DNA samples, genetic information, and other data, the results of which must be communicated to customers.*

3. Recommendations: Notification Requirements for Data Security Breaches at Government Entities

The Commission heard testimony from Chris Buse, Deputy Legislative Auditor with the Office of the Legislative Auditor, regarding current notification requirements for those affected by data security breaches at government entities, which are contained at Minnesota Statutes, section 13.055. Mr. Buse noted that, under that section's current definitions, "unauthorized acquisition" of data only occurs where the person obtaining, accessing, or viewing the government data has "intent to use the data for nongovernmental purposes." The LCDP recommends adopting the changes put forth in draft language presented to the Commission on December 7, 2018, which would delete the current language in section 13.055, subdivision 1, paragraph (c), containing the "intent" element.