

WRITTEN TESTIMONY FOR:

HF 1488: Legislative Commission on Data Practices and Personal Data Privacy
Minnesota House State Government Finance and Policy
Chairman Rep. Michael Nelson
March 18, 2021

March 17, 2021

Mr. Chair and Members of the Committee,

Citizens' Council for Health Freedom is a patient-centered, privacy focused organization with a mission to protect patient and doctor freedom. While I am the co-founder of this organization, which launched in 1998, I am also a registered nurse, a public health nurse, and author of *Big Brother in the Exam Room*. Thank you for this opportunity to provide testimony on H.F. 1488.

Patient privacy is critically important to the patient's wellbeing and trust. It's the foundation of a confidential patient-doctor relationship. Furthermore, the right to limit outside access to medical records is important to the doctor's ability to choose treatments specific to the unique needs and characteristics of each patient. As we say, "He who holds the data makes the rule."

In an age of COVID-19 where data collection and surveillance are increasing, it is vitally important to protect patient and individual privacy rights. Surveillance systems, government databases of patient encounters, vaccination cards, contact tracing, and electronic medical records threaten to erode personal and patient privacy—one law and one rule after the next.

CCHF has long supported patient control over the sharing and use of their personal and medical data, whether identified or de-identified. Consent requirements give patients the power to better decide the course of their care, to decide whether to participate in research, and to receive an unbiased second or even third opinion.

While we are not fans of establishing bureaucracies, the previous legislative commission was able to more thoroughly review complex privacy issues and contentious data proposals.

We believe there is value in having members "review and provide the legislature with research and analysis of emerging issues relating to government data practices and security and privacy of personal data," — as long as both sides are faithfully heard and considered. We also believe the rights of individuals and patients need protection from the many public and private entities that see personal and patient data as the 21st century version of "gold" and hope that legislators will give them free access—no consent required. We also hope that such a commission would protect the ability of doctors to provide patients with the personalized care that they need without being penalized for going outside standardized "protocols," as tracked by EHRs. Thank you.

Twila Brase, RN, PHN President and Cofounder