

**Prepared Testimony - HF 1726 (Thissen) – Health Records Act
Minnesota House Health and Human Services Committee
Tuesday, March 13, 2007
Start time: 11:54 p.m.
Presented by Twila Brase, president
Citizens' Council on Health Care**

Dear Mr. Chair and members of the Committee,

My name is Twila Brase. I'm am president of Citizens' Council on Health Care. CCHC has long been concerned with preserving patient and citizen privacy and protecting the confidential patient-doctor relationship.

House File 1726 is a major change in policy. This bill will permit broad sharing of private medical data by deleting significant patient consent requirements.

According to a letter from the Department of Health, the bill is the Department's "proposal for eliminating patient consent related barriers to the electronic exchange of health information. This legislation proposes 10 modifications to Minnesota's patient consent law..."

I have six points to make:

- The Record Locator Service (RLS) is a central registry created by placing certain patient data into it without patient consent. The RLS is created by a health information exchange—a term that this bill does not define. The bill is silent on serious issues surrounding the RLS:
 - Who's in the health information exchange that creates the RLS?
 - Who owns the data that's in the RLS?
 - Who can have access without consent?
 - Wow will patients be notified that their data is in the RLS?
 - Can their data be in more than one RLS? Again, who owns the patient's data?
 - Who's in control?
 - Who's accountable?
 - Who's to blame when the RLS is hacked the data is stolen or there's medical ID theft?
 - Who will compensate the patient who never consented in the first place? The doctor who pat the data in the RLS, the RLS, or the health information who created the RLS?
 - What's the role and access of health plans and employers beyond placing data into the RLS?

- The public is concerned about online medical records. According to a recent **Harris Poll**:
 - 62% haven't heard of the plan to create a nationwide health data system.
 - 42% think privacy risks outweigh expected benefits of a nationwide system of online medical records.
 - 21% want the right to not have their records online.

- The RLS will itself reveal private medical data. The pointing function will point to the fact that you've visited an oncologist, or a psychologist, or perhaps a cosmetic surgeon. How will the patient know what's been placed on them in the RLS? How will they feel safe giving consent for the treating physician to look into the RLS to find out where all their medical records are...and thus what kind of health care conditions they have?

- HF 1726 authorizes a breach in the private contract between a patient and doctor by statutorily permitting online disclosures of private data without patient consent. Furthermore, the liability section means that responsibility for any misuse or breach will be diluted.

- The definitions are problematic. For example, the definition of "non-clinical data" – the data that will be placed on each individual in the RLS to uniquely identify each individual could include your Social Security Number, your cell phone, your employer, or your drivers' license, etc.—all vulnerable to be hacked and used against the citizen. Furthermore, there is no definition of "representation of consent," but it appears to be an end-run around real informed consent.

- In combination with Minnesota Statute 62J – the law that allows the Minnesota Department of Health to access all the medical data on every patient in Minnesota— and their \$2 million Disease Surveillance funding request, the Department will be able to do what they were prevented from doing in 2003. Four years ago when the public got wind of their proposed rule to require hospital and health plans to send all our medical record data to the Department, there was a public outcry. The rule was withdrawn, but not the law. Thus, this bill will make it easier for the Department to gain access without the public even knowing.

HF 1726 does serious damage to our current medical privacy law. It also says that the patients' rights are secondary...and the desire of those who want to share data and build data systems and online medical records come first.

Patients need real consent, non-coerced consent. This bill reduces consent rights and should not move forward without it.

Thank you.