Take Action Today!

This is a rare opportunity for action on medical record privacy and data control. The MN Dept of Health wants your comments on patient consent before accessing private medical records, on having to inform patients about unauthorized access to medical records, and on whether patients should be able to see the electronic logs that show exactly who accessed their medical records, when, where, and why.

You almost didn't get this opportunity (see below - CCHF Forces Action)

Below:

• Deadline for Comments - Next Thursday, Dec. 20
• Sample Comment on the 3 questions
• Addresses for Email/Mail
• CCHF Forces Action
• History of Issue

DEADLINE FOR PUBLIC COMMENT: Thursday, December 20.

SAMPLE COMMENT: (if use this, please revise at least one line and make at least one personal comment of your own to personalize it so it can't be dismissed as a "form letter")

Dear Commissioner Edward Ehrlinger,

Your department has asked for comments on three questions related to medical record access. I have a question. Why are there no questions about how the public feels about the very terms and assumptions behind the questions.

I have learned that "representation of consent" means everyone from hospitals to clinics to researchers to contractors and others can access to my records without having my actual consent in hand; without being positively sure I said yes. Also, why is the question not also about "unintentional unauthorized" and how is "authorized access" defined? Too often the forms I'm asked to signed at the doctor's office have only one signature line for all sorts of things above including consent for treatment. Are people sharing my information for non-treatment activities without my true consent?

My data is my data. No one should look at it or use it just because someone claims they have my consent. And as with anything else I own, I should be able to control who's using it and to know who's been looking at it and why. That's what legislators needs to
know and should be told. Make sure that my concerns are in your report to the legislature.

Name
City, MN

EMAIL COMMENTS TO: MN.eHealth@state.mn.us

OR MAIL TO: Minn. Dept of Health, 85 East Seventh Place, Ste 220, P.O. Box 64882, St. Paul, MN 55164-0882

DEADLINE: Next Thursday, December 20, 2012

CCHF FORCES ACTION:

On December 6, the MN Dept of Health held a brief public hearing with info on this issue. There was hardly anyone in the room, except for a few lobbyists. MDH says KSTP was there and 20 people that weren't MDH folks. When comments were requested, CCHF’s president (yours truly) was the only one to speak. I asked how the public could even understand the questions that were being asked. I asked if there was a document somewhere explaining terms like "representation of consent." There wasn't. I asked them to make one. I emailed later to see when it was going to be released.

The document is now written, and as a result of our request they extended the public comment deadline a week to Thursday, December 20.

Please comment today.

States have power to write real privacy laws. Help legislators take a strong stand for real consent, limited consent, and the right to stay off the National Health Information Network. The NHIN is being created by $27 billion from the Recovery Act (stimulus). It will share your data with 2.2 million entities as authorized under HIPAA and HITECH (an act within the stimulus bill). The federal HIPAA law allows state privacy laws to supercede HIPAA’s no-privacy law.

HISTORY OF ISSUE:

Broad Data Sharing - Hospitals and clinics with electronic medical records are using your data in ways that you cannot imagine. Many signs consent forms without reading them. Your data is being widely used and accessed.

When legislators supported a broad study of access, -- and wanted to repeal "representation of consent" -- every hospital and health plan lobbyist emerged from the woodwork to say no. They physically surrounded legislators in the HHS conference
committee, all working together to strip the repeal from the bill and reduce the study into almost nothing. They didn't want full access to records studied and they didn't want patients to access the audit logs, which show who accessed patient data when, where and for what.

Mary Krinkie, lobbyist for MN Hospital Association, testified about various ways they "share data once we have patient consent outside of just treatment situations" and also said:

....we are thinking about how we can use data and information in creative ways to help bend the cost curve. And so we just have to think about the changes as Mr. Griffin said about how we can use data with patient consent we don't want it limited to just medical treatment, operations and payment. (HHS Conf Comm, 5/2/12)

Phil Griffin, lobbyist for Fairview, said stripping out "representation of consent" would "interfere with the ability of organizations like ours to move data in ways that you are asking us to move as we move towards new systems for payment." He later disagreed with Rep. Mary Kiffmayer's assertion that the patient owns the medical record:

"Representative Kiffmayer, let me just back up a bit and say I'm not sure I agree with your analysis of Minnesota statutes that the medical record belongs to the patient."

The lobbyists got the study shrunk to just three questions...and they are not even written as questions. But you can help CCHF heighten this important issue of privacy and control. They want it hidden. We want it out in the open.

"Representation of Consent" - Minnesota has a "representation of consent" law, which CCHF opposed in 2007 when it was adopted as part of a revised health records law. In short, the clinic or hospital or pharmacy or whomever only has to "represent" that they have a signed and dated consent from you to the person who wants to access and use your data either by grabbing it online or taking it out of your electronic medical record. They don't have to prove they have it to the requester. They just have to declare they do. They may not even pull it out and look at it to see if you really signed it or if you deleted a portion of it because you refused to share the data.

Please comment today! Deadline is Thursday, Dec. 20.