

Citizens' Council on Health Care
1954 University Ave. W., Ste. 8
St. Paul, MN 55104

January 18, 2005

Office of the Nat'l Coordinator Health Information Technology
U.S. Department of Health and Human Services
Attn: NHIN RFI Responses,
Hubert H. Humphrey Building, Room 517D
200 Independence Avenue, SW
Washington, DC 20201

RE: NHIN RFI Responses

Thank you for requesting public comment on implementing the President's call for widespread adoption of interoperable electronic health records by 2014—the National Health Information Network (NHIN) discussed in the Federal Register notice dated November 15, 2004.

I will focus on the charge of a compelling public interest, the Request for Information, and the term “interoperable.”

Compelling Public Interest

The notice states, *“Regardless of how it is developed, overseen or operated, there is a compelling public interest for a NHIN to exist.”*

This claim does not stand up to scrutiny. Nor is it supported by any documentation. There is no evidence that the public is asking for a national electronic medical records system that will facilitate the sharing and dissemination of their private medical records.

In fact, the public has continually expressed concern with the move to digitize, share and access their private medical information, especially without their knowledge or consent. For example, more than 52,000 public comments were sent to HHS in response to the November 3, 1999 proposed federal medical privacy rule, many of them demanding patient consent requirements that were no where to be found in the proposed rule. Patient consent was partially added to the first final rule issued on December 28, 2000. However, after health care industry expressed concerns to the administration, the Rule was modified and re-drafted. For all intents and purposes, patient consent requirements were eliminated and new access through a “limited data set” was added. An additional 11,400 comments were elicited from the public, but despite the public's expressed concerns, these provisions did not change. Federal law no longer recognizes a need for patient consent for most sharing of patient data.

Request for Information

The November 15 notice is not a request for the public's comment on whether the NHIN is a good idea. The notice presumes moving forward with the President's call regardless of the public's opinion. Far better for the RFI to have been a request for the public's view of a national interoperable health information system. Instead the RFI is a request for working definitions, type of models to be considered, and level of national scope versus local scope. It is essentially a request for technical assistance, not a request for the public's perspective.

Interoperability

According to the Federal Register notice dated November 15, 2004, "Interoperability" is defined as *"the ability to exchange patient health information among disparate clinicians and other authorized entities in real time and under stringent security, privacy and other protections."*

Unfortunately, the federal "medical privacy" rule, without which the NHIN could not have even been proposed, has significantly expanded the term "authorized entities."

In addition, as stated previously, the rule does not provide stringent protection of patient privacy or data security. Data can be shared without the patient's consent for innumerable purposes, including payment, treatment and "health care operations." These three terms are more broadly defined than most of the public could ever imagine them to be. Furthermore, HHS has already acknowledged that data collected through the "limited data set" remains identifiable. Finally, §164.512 of the rule permits broad sharing to government agencies, law enforcement, and other entities. Notably, the section is called, "Uses and disclosures for which an authorization or opportunity to agree or object is not required."

The November 15 notice also says *"Interoperability is necessary for compiling the complete experience of a patient's care, for maintaining a patient's personal health records and for ensuring that complete health information is accessible to clinicians as the patient moves through various healthcare settings. Interoperability is needed for clinicians to make fact-based decisions so medical errors and redundant tests can be reduced. Interoperability is also critical to cost-effective and timely data collection for biosurveillance, quality measurement and clinical research. In short, interoperability is essential for realizing the key goals that are desired from health information technology."*

This statement of need is not written from the perspective or needs of patients, and indeed would not likely meet the muster of most patients and citizens. Many patients go to great lengths to make sure that one practitioner is not given the information created by another practitioner, especially if one practitioner's information is viewed as biased, judgmental, or inaccurate. In addition, some patients want a fresh, untainted second opinion.

The notice asserts that the system of electronic medical records (EMRs) will facilitate access to facts for decision-making. However, patients are not just a collection of lab results and vital statistics. History and personal information are as important to a medical diagnosis and treatment plans as lab values and pulse rates. This important aspect of the EMR will only be correct to the extent that patients choose to divulge. However, as patients realize how broadly their data will be disseminated in the proposed system, those “facts” may not be divulged, and what is divulged may or may not be true.

The California Healthcare Foundation survey found 15 percent of the American public already taking evasive action to protect their medical privacy. This includes falsifying medical questionnaires, asking data to be omitted from their medical records, and using a false name. That data was collection in late 1998, before the federal “medical privacy” rule was finalized—before inordinate data sharing was authorized by HHS.

In addition, electronic medical records are no less susceptible to error, and in fact may be susceptible to additional inaccuracies due to data entry errors.

Finally, biosurveillance, quality measurement and clinical research (the fourth goal of the Framework) are not the goals of most patients. These remain priorities for government agencies, third party payers, and medical researchers. Patients are concerned about limiting access to these entities. A Gallup Poll found 92 percent opposed to giving government agencies access, and 84 percent opposed to providing access to insurance companies without prior consent.

Conclusion

HHS has not yet proven that it has the support of the American people to create a national health information network, or further, that the American people have even been informed about the most rudimentary details of the plan. No evidence is shown for assertions about a “compelling public interest.” Finally, current law in the form of the federal “medical privacy” rule does not provide stringent privacy and security protections for patients as asserted in the November 15 notice. In fact, there is less protection now for patients than before the rule was written.

Therefore, the NHIN initiative should not move forward until a true public mandate is shown, the public is fully apprised of the plans and provided an opportunity to comment, and the right of prior patient consent for sharing and dissemination of private medical record data is restored to the American people.

Sincerely,

Twila Brase, RN
President
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