



June 10, 2010

The Honorable Pat Quinn  
Governor of Illinois  
James R. Thompson Center  
Suite 16-100  
Chicago, IL 60601

RE: House Bill 6441

Dear Governor Quinn,

On behalf of the American Civil Liberties Union of Illinois, I write to share with you our concerns regarding both patient privacy and the security of medical records that arise as a result of creating the Illinois Health Information Exchange Authority (“Authority”) under House Bill 6441. As Illinois and, indeed, the nation moves toward digitizing all medical records and information, patients will expect that the privacy of their medical data is protected and controlled by the patient; and, that the security of all medical data be protected from security breaches. In order to ensure patient privacy and data security, specific systems will need to be built in from the start – for it will be incredibly costly to fix flaws in privacy protections once the Health Information Exchange (“Exchange”) is operating.

To address these concerns, we urge that you use your power of appointment to insure that *at least* one member of the new Authority that will oversee the Exchange reflects the importance of patient privacy and data security. Such an individual, or organization, can assist the Authority in identifying privacy and security issues from the outset, allowing the Exchange not only to assist in assuring quality health outcomes but also protect the basic privacy of millions of persons in Illinois.

A number of issues need to be considered by the Authority in the early process of constructing the Exchange, including:

- Requiring affirmative consent from patients before their health information can be uploaded to a shareable electronic data base, and ensuring that the information cannot be accessed by a provider without specific patient consent.
- Creating the ability for patients to designate some records as “sensitive health care” information about themselves, and permit such sensitive information to be

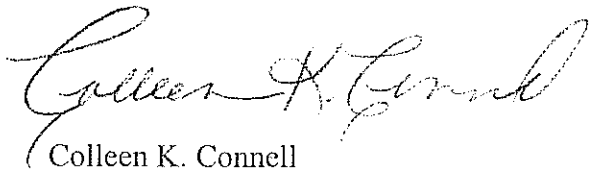
segregated so that certain providers can only see parts of a person's health records.

- The Exchange should permit minors to segregate health information so that services to which a minor has consented on his or her own (under current Illinois law) can be uploaded to the Exchange for future reference but not be available to his or her parents; and,
- Specific policies and procedures should require that providers give notice to their patients that their information is to be shared with the Exchange.
- Specific policies and procedures regarding data security and threats originating from outside the Exchange.

We understand that the digitization of medical records is a critical part of national health care reform adopted earlier this year by Congress. For health care to work and function in the best interest of patients across Illinois, it is critical that the Illinois Health Information Exchange Authority carefully consider these questions, among others, as it sets the rules for such an Exchange in Illinois. The ACLU of Illinois has been studying these issues for years, and we have a national network of experts and interested parties who are examining "best practices" being adopted by other states. We stand ready to assist the Authority in assuring that data security and the privacy of patients remain primary values and goals in moving the State of Illinois toward a day when most medical records are digitized.

We would welcome the opportunity to discuss this issue with your staff -- or you -- in the near future. We know that you are concerned with data security and patient privacy. The State needs to get this right at the beginning both to assure privacy and security and save resources in the future. We look forward to hearing from you.

Sincerely,



Colleen K. Connell  
Executive Director

CC: Michael Madigan, Speaker of the House  
John Cullerton, Senate President  
Don Harmon, Illinois State Senate  
Julie Hamos, Director of the Department of Healthcare and Family Services