

October 3, 2011

Health Information Technology Exchange of Connecticut
Attention: Lori
c/o Planning Branch, Connecticut Department of Public Health
P.O. Box 340308, MS#13PBA
Hartford, CT 06134-0308

and by email
Legal@hitect.org

Dear Ms. Reed-Fourquet:

I am writing on behalf of the CT Health Policy Project to comment on the HITE-CT proposed Consumer Authorization and Consent and Consumer Rights policies. The CT Health Policy Project is a statewide nonprofit consumer advocacy organization dedicated to improving access to affordable, quality health care for every Connecticut residents. We assist consumers struggling to access health care across the state, provide policymakers with independent, balanced policy analysis and train future state health policy leaders. We have grave concerns that your policies for health information exchange will jeopardize access to care and undermine a critical improvement of our broken health care system. I have raised these concerns about the proposed opt-out privacy policy repeatedly with HITE-CT.

We at the CT Health Policy Project have long been strong supporters of health information technology and exchange. Interoperable electronic health information will be a critical driver of health care system reform in our state, will improve patient safety and is one of the few ways to save money in the system that improves efficiency and does not involve shifting costs between stakeholders, most often onto consumers. Improving the appropriate flow of information will reduce costs, improve quality and make our health system more efficient. Providers need comprehensive, valid, up-to-date medical information whenever they treat a patient to ensure the best health outcome.

However, protecting patients' privacy and the security of data is paramount. Not only are legal challenges complex and shifting, but the public must have the strongest trust in the system eventually adopted in Connecticut for it to be widely accepted and effective. Trust in the privacy of sensitive consumer health information should be a top priority for HITE-CT. Even the perception of inadequate privacy protections and policies would undermine and significantly damage the system's effectiveness. Your proposed opt-out privacy policy will protect neither consumers' privacy or the integrity and long-term sustainability of the exchange.

It is critical that every consumer who shares information in the exchange has made an informed decision. If public trust in the integrity of the system is eroded, even before implementation, resulting in low participation by either consumers and/or providers, the system will be useless. Even one case of a

breach of information about a consumer who did not affirmatively agree to share their information, and surrounding publicity and legal challenges, could bring the entire system to a halt.

Several types of sensitive information are protected by state and federal law and cannot be shared on the exchange without affirmative patient consent. Expecting providers to identify each instance of protected information in all information shared on the exchange is unrealistic, as is the expectation that providers will accept the liability for the integrity of that identification. As you are aware, all of our surrounding states successfully use an opt-in privacy policy potentially complicating the care of state residents who try to access care in another state. The experience of opt-in states is that between 86% and 98% of patients agree to share their information on the exchange and sign the opt-in consent form.

I urge you and HITE-CT to revise the Consumer Authorization and Consent and Consumer Rights Policies to incorporate an opt-in privacy policy ensuring the integrity, public support and long term sustainability of the HITE-CT exchange. Thank you for the opportunity to provide our comments.

Sincerely,

A handwritten signature in cursive script that reads "Ellen M. Andrews".

Ellen Andrews, PhD
Executive Director