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TESTIMONY to the Public Health Committee

March 16, 2012

Re: SB-368, An Act Concerning the Health Information Technology Exchange of Connecticut

Ellen Andrews, PhD
Executive Director

Thank you for the opportunity to share our support for SB 368 and to thank the committee for raising this important bill.

We at the CT Health Policy Project have long been strong supporters of health information technology and exchange. Interoperable electronic health information exchange will be a critical driver of health care system reform in our state, 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 systems more efficient. Providers need comprehensive, valid, up-to-date medical information when they treat a patient to ensure the best health outcome.

Public trust in the integrity of the system is critical. While it is critical that your doctor sees your sensitive health information, your neighbor, your employer or a marketing firm should never see it. Strong privacy protections are essential to the integrity of the system. The public must have the strongest trust in the Connecticut's system for it to be widely adopted and effective. Trust in the privacy of sensitive consumer health information should be a top priority. Even the perception of inadequate privacy protections would undermine and significantly damage the system's effectiveness. It is critical that every consumer who shares information in the exchange has made an informed decision. If the public cannot trust the integrity of the system, it will result in low participation by consumers and providers and 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.

The HITE-CT Board has adopted a controversial opt-out privacy policy that will default every state resident into the system unless they affirmatively ask to be taken out. Consumer advocates and providers have grave concerns about this proposal. Busy hospitals and doctors' offices do not have time to edit every patient record for sensitive information nor would they be likely to accept the liability. Even if they agreed, inevitable human editing errors would expose patient information and expose providers to lawsuits. Providers would never know if they are seeing the complete medical record. Critical medications or treatments for sensitive conditions, such as HIV or behavioral health, may have been omitted by other providers, canceling out one of the most important advantages of electronic medical records. If providers decide this is too much to take on and don't participate in the exchange, the system will fail.

An opt-in policy is consistent with our surrounding states. NY, RI and MA all have adopted an opt-in privacy policy for health information exchange where patients indicate their consent to have their information shared with their signature. In those states, between 86% and 97% of consumers agree to share their information.¹ If

Connecticut adopted an opt-out recommended policy, patients seeking care in surrounding states would face consent complications potentially disrupting care.

Either policy requires significant patient education. To responsibly administer an opt-out policy, HITE-CT must devote significant resources and attention to fully explaining the risks and benefits to patients. However, HITE-CT has proposed only \$35,000 for patient education in their \$7 million budget. In an opt-in system, the process of soliciting consent is an educational opportunity to help patients understand health information exchange. The first time a patient hears about the exchange should not be in the event of a breach.ⁱⁱ

I urge you to pass SB-368 protecting patients' sensitive health information and ensuring the viability of our state's essential health information exchange. Thank you for your time and your commitment to improving the welfare of every Connecticut resident.