

TESTIMONY to the Human Services Committee

March 17, 2011

In favor of HB 1147, AAC Patient Consent for the Exchange of Electronic Health Information

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Thank you for the opportunity to share our support for HB 1147 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. E-health initiatives are unique in health system reform proposals, gaining support from virtually all sectors and stakeholder groups in a contentious health care environment. 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 whenever they treat a patient to ensure the best health outcome.

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 system eventually adopted in Connecticut 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 and policies 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 public trust in the integrity of the system is eroded, 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.

Since its inception, I have been a consumer representative on the eHealthCT Board of Directors, a nonprofit organization dedicated to supporting health information exchange. A year ago we convened a diverse group of stakeholders to develop a privacy and security policy for eHealthCT's Medicaid health information exchange pilot. We engaged a large and diverse group of stakeholders including legal aid, legal privacy experts, HIT experts, communications experts, labor, state agencies, payers, providers, advocates for people with HIV/AIDS, mental health and substance abuse problems, and for whom English is a second language. We held well-noticed public forums in this building, solicited comments and questions online, and worked to inform

stakeholder groups, particularly consumers and trusted consumer groups, about the considerable benefits of health information exchange, as well as the risks. Over several months and a great deal of research on other states and federal regulations, we developed a strong, consensus, feasible opt-in privacy policy as described in HB-1147. That policy is being used now successfully in eHealthCT's health information exchange pilot with several Connecticut hospitals and clinics.

A current proposal by a state task force planning committee recommends a controversial opt-out privacy policy that will default every state resident into the system unless they affirmatively ask to be taken out. Because certain sensitive health information cannot be shared without affirmative patient consent under state law, the group is proposing that providers be responsible for removing that information from any records that are shared. Consumer health and privacy advocates 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.

Our surrounding states have adopted an opt-in privacy policy for health information exchange where patients indicate their consent to have their information shared with their signature. If Connecticut adopted the task forces' opt-out recommended policy, patients seeking care in surrounding states would face consent complications potentially disrupting care. In a study of Massachusetts' opt-in policy, 88 to 92% of patients agree to share their medical records in the exchange.ⁱ

I urge you to pass HB-1147 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.

ⁱ M Tripathi, et. al., Engaging Patients for Health Information Exchange, Health Affairs 28:435- 443, March/April 2009.