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**Testimony of Sheldon Toubman before the Public Health Committee in Support of SB 368**

Good afternoon, Senator Gerratana, Rep. Ritter and members of the Committee. I am a staff attorney with New Haven Legal Assistance Association and I am here to testify in support of Senate Bill 368, which would establish a system of affirmative opting in for the new electronic health records (EHR) system now being developed.

At the outset, I want to be clear that, as an attorney who regularly represents low-income health consumers who often receive untimely or even inappropriate care because of a lack of good quality communication among health providers, I whole-heartedly endorse the new EHR system. This system will finally allow for timely and accurate communication among all providers so that misdiagnoses and redundant (and expensive) tests can be avoided, and proper treatment can more efficiently and effectively be implemented. Inter-operable EHRs will be a critical driver of health care system reform in our state, will improve patient safety, and is one of the ways to save money without shifting costs onto consumers. This has been a long time coming and we all need to get behind it, including by encouraging as many health consumers as possible to join it.

But we also need to understand what this system means: Any provider or authorized employee in a provider's office can, with a few clicks of a mouse, receive complete medical information on any patient in the state. Although ethical obligations would prohibit providers from viewing records of individuals who are not patients of theirs, there is nothing mechanically stopping any one of tens of thousands of providers and provider employees from accessing such personal information, if they choose to.

Given the power of this tool, we need to proceed in a fashion that the public will fully respect and support. Protecting patients' privacy and the security of their data is paramount. The public must have the fullest trust in the system adopted in Connecticut for it to be widely accepted and effective. Even the perception of inadequate privacy protections and policies would undermine the system's effectiveness.

The board of the Health Information Technology Exchange of Connecticut has proposed a policy for the EHR system which I am afraid threatens this trust. Specifically, it has proposed that individuals be **automatically included** in the exchange unless they affirmatively opt **out**. Under such a system, it is unlikely that even a majority of consumers would have made an informed decision to share information in the exchange. The only way to be certain that patients have received a notice of their rights and had an opportunity to exercise them is to require a signature on the notice, with an option on the notice they sign to opt in. An opt out system would

bypass this basic level of informed consent. Even one publicized case of a breach of information about a consumer who did not affirmatively agree to share his or her information could bring the entire system to a halt, threatening the critical gains in health care delivery that will be possible under it.

The policy in SB 368 is hardly new. It is in keeping with Connecticut's long-standing tradition of affirmative informed consent for sharing of personal medical information. This is embodied in Sec. 20-7d of the Connecticut General Statutes:

A copy of the patient's health record, including but not limited to, x-rays and copies of laboratory reports, prescriptions and other technical information used in assessing the patient's condition shall be furnished to another provider *upon the written request of the patient*. The written request shall specify the name of the provider to whom the health record is to be furnished. The patient shall be responsible for the reasonable costs of furnishing the information. (emphasis added).

Beyond this, several types of sensitive information are specifically protected by state and federal law and cannot be shared on the exchange without affirmative patient consent. Under the HITE-CT board's policy, the records of all individuals would be uploaded into the system regardless of such releases. Expecting providers to identify each instance of protected sensitive information, for every patient who has **not** affirmatively opted to share this information, and to delete each such reference from the records otherwise shared with the exchange, is wholly unrealistic.

Adopting SB 368 will go a long way toward solving these problems. And the EHR exchange consent form can be integrated into a HIPAA form, creating no new work for office staff.

Some have argued that, notwithstanding our long-standing state law traditions of affirmative consent for release of personal medical information, we need a special opt-out procedure for the new electronic system because otherwise folks won't participate in it and we will lose its value. But all of our surrounding states successfully use an opt-in privacy policy. The experience of opt-in states is that a vast majority of patients agree to share their information on the exchange and sign the opt-in consent form. For example, in Massachusetts, 90% participated in a demonstration EHR system which required such consent.

Yes, this may require a provider to take a few minutes to explain the new system and the benefits of joining it, as they do about taking a diagnostic test or trying a new drug. But patients expect and deserve this. No system founded on trust should operate any differently.

For all of us, the success of the exchange is critical. Passing SB 368 and thus requiring that individuals affirmatively opt to participate in the EHR system will ensure the integrity, public support and long term sustainability of the HITE-CT exchange.

Thank you for allowing me to speak before you today.