

Public Comment submitted to the CT Health Information Technology and Exchange
June 23, 2010

Ellen Andrews, PhD
Executive Director
CT Health Policy Project

Thank you for this opportunity to provide feedback on your Strategic Plan and planning process to develop an HIT Exchange for Connecticut. 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, 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.

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 adopted and effective. Trust in the privacy of sensitive consumer health information should be a top priority of your plan. Even the perception of inadequate privacy protections and policies would undermine and significantly damage the system's effectiveness.

Unfortunately it is my understanding, although I did not see it outlined in your draft plan, that this group has endorsed an opt-out privacy policy. This would be a grave mistake. I will leave it to others to describe the significant legal challenges, but the policy and public trust implications are deeply concerning. 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. A strong public education campaign, in either an opt-in or opt-out environment, is critical. However, effective communications efforts rely on the endorsement of trusted public messengers who will be unlikely to support an opt-out policy.

I have been a consumer representative on the eHealthCT Board of Directors since its inception. In that role, together with Brenda Kelly of AARP and Kevin Carr, last year 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.

It is unfortunate that you do not have consumer representation on this group and I fear that you will not receive much consumer feedback on your plan. This forum was not publicized and your draft plan has not been disseminated. I urge you to reject this policy recommendation and follow the wisdom of eHealthCT's larger public process and adopt an opt-in privacy policy. Thank you for your time and attention to this important issue.