

DPH proposing weak privacy protections for Connecticut health information exchange

With federal funding, the CT Department of Public Health (DPH) is leading a group planning a health information exchange for Connecticut, a very good thing, but they are recommending 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, such as HIV status and mental health treatment, cannot be shared without affirmative patient consent under state law, DPH 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 policy proposal.

Moving patient records from paper to electronic files that can be shared is an important innovation in health care systems in Connecticut and across the US. It is one of the few health care reforms that most everyone agrees with. Electronic records will improve the quality and timeliness of care, reduce medical errors, save money, reduce duplicate testing, and generate data on the health of our state. If you show up unconscious at an emergency room, you want the doctor there to have all the information he needs to make you well and safely treat you.

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 DPH wants to build.

Advocates have a number of concerns about DPH's recommended opt-out privacy proposal.

- **Public trust is critical.** If patients are not confident that their privacy will be protected and that they control access, few people will participate and the system will fail.
- Hopefully it never happens, but **if there is ever a breach of personal information for a patient who didn't consent to share his information there will be a public outcry**, and rightfully so.
- **Busy hospitals and doctors' offices do not have time to edit every patient record** for sensitive information nor will they be likely to accept the liability. Even if they agree, inevitable human editing errors will expose patients' information and expose providers to lawsuits. If providers decide this is too much to take on and don't participate in the exchange, the system will fail.
- States that have adopted opt-in policies, rather than DPH's opt-out proposal, find that the vast majority of patients agree and sign up. **When explained well, most people see the benefits** of having their providers know all their medications, surgeries and allergies without having to remember them. **It isn't really necessary to default people into the system.**
- **Providers would never know if they are seeing the complete record** in DPH's proposed system. 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.

- **DPH's committee making this decision included no consumers or advocates** and did not use a public process to develop their proposal. The subcommittee that developed the proposal held a poorly publicized forum after they had already voted on their recommendations.

Sadly DPH had a model of inclusive, thoughtful privacy policymaking here in Connecticut. Last year eHealthCT, a nonprofit that includes consumers, providers and policymakers, after a lengthy public process, consulting with legal and technology experts, adopted an opt-in policy for a pilot Medicaid health information exchange. eHealthCT's policy include a strong consumer education component and a requirement that patients sign a form before any information is shared, similar to successful systems in other states.

Advocates are working with policymakers to reverse DPH's recommended default privacy policy. **An opt-in consent policy is critical to developing a viable, secure health information exchange that engages and respects Connecticut consumers.**

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