

First eHealth Consumer Privacy Forum

April 20, 2009

CT State Capitol, Hartford

The Connecticut Health Policy Project and AARP- CT hosted a forum at the State Capitol in Hartford on April 20, 2009 about electronic medical records – *eHealth: Why Consumers Should Care*. The purpose of the forum was to provide information about electronic medical records and to get input from advocates and consumers on privacy and security issues. Electronic medical records and sharing them are important aspects of improving the quality of medical care, reducing costs, and reforming our health care system. Speakers included Kevin Carr, MD, from Trusted Medical, Brenda Kelley of AARP-CT, and Ellen Andrews from the CT Health Policy Project.

Ellen Andrews outlined the problems with the health care system in Connecticut including quality lapses, rising costs, and increasing rates of chronic disease. 17% of Americans report that test results or medical records were not available at a medical appointment in the last two years; that rate is twice as high for low income as for higher income patients. The potential benefits of electronic health information include preventing medical errors, coordinating care, improving public health surveillance, reducing paperwork, improving efficiency, saving money, and making health care more affordable for everyone.

Ms. Andrews emphasized that consumers and their advocates have an opportunity to build Connecticut's health information system with security and privacy incorporated from the beginning. This forum is the beginning of a conversation, not an end. There is a great deal of federal money and coordination coming to ensure that health information technology grows and succeeds. All stakeholders, in Connecticut and in Washington, are welcoming, even seeking, consumer input into the design of systems.

Dr. Carr described what health information technology is. The Institute of Medicine wants to improve patient safety, efficiency, and quality and believes that Health Information Technology, including electronic medical records is a way to do this. Electronic medical records can facilitate better communication with patients. For example, the doctor can print out a list of medications for the patient so that he or she knows exactly what they are taking as well as the dosages. It is easier to track historical medical information and chart patients' medical information.

Unlike paper, electronic charts allow patients to track who has accessed their information. With electronic records there is an audit trail, electronic evidence of who looks at a chart as well as exactly what they looked at. With paper charts, there is no record of who has looked at a chart or what they reviewed.

Extensive work has been done and will continue to be done to ensure that electronic medical record systems are secure and that computer hackers are kept out. Some of the risks of electronic

medical records are loss of information, inaccurate information, inappropriate release of information, and sale of data for commercial purposes. One of the purposes of the forum was to get advocate and consumer input on these issues.

Dr. Carr described electronic medical records and gave a few examples so the audience could see what they look like. He showed a fictional electronic medical chart for a patient with allergies and a list of what medications the patient is taking. Dr. Carr emphasized that electronic health records put patients at the center of health care. The purpose of sharing health information through electronic medical records is to improve medical care.

The audience was involved in the discussion by asking questions and sharing their concerns. Vicki Veltri, from the Office of the Health Care Advocate, asked about quality control methods for entries into the electronic medical record. Dr. Carr responded that one solution is using dropdown lists for data entry to reduce errors. The system will also “flag” an entry if necessary information has been omitted and the person will be directed to enter this information. A follow up question was asked about double checking information that is entered into the system so that the wrong information doesn’t get carried forward. Dr. Carr responded that everyone in the office has to be taught to validate important information. An audience member wanted to know how they would ensure that information goes to all of the medical professionals that need it. Dr. Carr said that using a password would help with this issue.

Shawn Lang, from the CT AIDS Resource Coalition, asked about how patients with HIV could control the sharing of information. Dr. Carr responded that this needs to be addressed in Connecticut. In other states, the information might only be released to a primary care doctor. If the patient doesn’t want to share it with other doctors he or she can opt out of showing that information. Then there’s the related issue of HIV medications that the patient may be taking because those are recognizable as HIV drugs.

There will be a pilot project with Medicaid patients in Connecticut and electronic health records to be implemented at the end of 2009. Through this project funding is available to hire attorneys to answer legal questions concerning privacy and security.

Another audience member asked how information would be shared between states and if we would be risking having silos of information with just health information technology in Connecticut. Dr. Carr replied that the federal Office of the National Coordinator wants states to take the lead by creating an infrastructure that will evolve into a national structure. States are communicating with one another to address these issues and there will be more work on coordinating information exchange between states.

Jill Zorn, from the Universal Health Care Foundation, asked who owns the medical record because most doctors’ offices think that they do, but ideally the patient would. The data in the system is seen as belonging to the providers. When the information is being exchanged it becomes the patient’s and it is under the patient’s control.

Vicki Veltri, General Counsel for the Office of the Health Care Advocate, was very concerned about medical records being sold to insurance companies for purposes of setting rates or denying

coverage and argued strongly this should not be allowed to happen. Dr. Carr said that they would follow the rules established for the governing body of Health Information Exchange and her concerns would be included in the development of those privacy policies.

Deb Polun from the CT Commission on Aging wanted to know if long term care is included in the development of electronic medical records. Dr. Carr said that nursing homes are often less advanced technologically but this is something that should be addressed.

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An audience member wanted to know more about the pilot program and if there is a timeline. Is eHealth CT the designated entity as mentioned in the federal stimulus package? This hasn't been decided yet. The pilot will be small and the timeline is still being determined.

In her closing remarks, Brenda Kelley described Health Information Technology as an essential building block for health reform and economic recovery. It can also improve quality and efficiency, as well as saving lives and reducing costs. Patients can review or comment on their health records, which they usually don't have the opportunity to do with paper records. It is also possible to limit who has access to certain parts of the medical record, if a patient would like to keep certain information confidential.

Connecticut is in the early stages for electronic medical records. It is essential to establish a solid foundation concerning privacy and security issues to earn consumer confidence.

This is the beginning of what will be an ongoing conversation about privacy and safety issues with electronic medical records. The CT Health Policy Project will be developing a resource page on our website for advocates to follow and join the discussion. For more information or to become part of the process, continue to check our blog or email us at information@cthealthpolicy.org. Also check CT-N <http://www.ctn.state.ct.us/> for recorded coverage of the event.

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