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For Immediate Release
September 17, 2012

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Nationwide Health Information Network Implementation to Proceed Without Formal Regulation: CCHF Urges States to Protect Citizens' Health Information

Key Facts:

- The Office of the National Coordinator for Health Information Technology (ONC) announced that it will not regulate the deployment of the nationwide health information network, instead providing guidelines and best practices for implementation of individual “trusted exchanges” by states or individual health plans or providers.
- Citizens’ private health data will flow through and be housed within the nationwide health information network putting patient data at risk for privacy breaches.
- The *Citizens’ Council for Health Freedom* urges states to enact stricter legislation to protect its citizens’ private health data while it resides on state portals that connect to the nationwide health information network.

ST. PAUL, Minn. – The Office of the National Coordinator for Health Information Technology (ONC) announced earlier this month that it will not regulate the nationwide health information network, or NHIN, through formal rule-making, instead offering “a framework of principles and good practice models” to help guide deployment without hindering the implementation. The NHIN is designed to share patient health data among insurers and all types of health providers that an individual may seek treatment from. The nationwide network will interact with all state and individual provider networks, to ensure that information follows patients.

The problem inherent in the NHIN, and in all electronic health information networks, is privacy. Patient data will be widely shared, and often without the knowledge or informed consent of the patient. The current announcement by the ONC should highlight this critical issue, but does not.

In essence, according to ONC, the federal government will pay \$20 billion in financial incentives to build the electronic health information network, which will be used to share and transfer private patient health information on vendor, state and federal health information networks, but will not issue regulations to require patient consent before patient data is accessed or shared.

“While the lack of patient consent over data sharing in the NHIN is troubling, an even more critical concern is the fact that Americans are unaware of the existence of this ‘network of networks’ and how their information will be shared,” said Twila Brase, President of the Citizens’ Council for Health Freedom. “If they were aware, they could act. Most people believe that the HIPAA privacy rule protects private health information, when in actuality it enables broad sharing with approximately 2.2 million entities. And without federal patient consent requirements in law or regulation, private health data becomes even more vulnerable to security breaches and to being used in ways objectionable to patients.”

The Citizens’ Council for Health Freedom proposes a solution. Under HIPAA regulation, states are entitled to enact stricter legislation in order to protect the privacy of patients as their information is transmitted over and housed within the NHIN. States must act quickly to protect patient data legislatively before the NHIN is operational.

“Since HIPAA allows for tighter control over patient data sharing through state legislation, the best hope for protecting patient data that flows through the NHIN is by state regulation,” remarked Brase. “For example, in Minnesota, we were able to protect data legislatively through passage of a law stating that patients must be informed and then consent to the sharing of their data with a specific provider, and the provider must have their consent in writing before they are able to access a patient’s records through the NHIN. This allows patients greater understanding and control over who is accessing their records when, and for what reason. Every state should take steps to enact precautionary, patient-protecting legislation in order to ensure the safety and privacy of each and every citizen.”

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Twila Brase is president and co-founder of the ***Citizens’ Council for Health Freedom***. She has been called one of the “100 Most Powerful People in Health Care” and one of “Minnesota’s 100 Most Influential Health Care Leaders.” The Council’s efforts have stopped government-issued treatment directives, added informed consent requirements for access to patient data and defeated a proposed Health Insurance Exchange. Brase’s daily radio commentary, ***Health Freedom Minute***, is a 60-second radio address on pressing health care issues. She has been interviewed by CNN, Fox News, Minnesota Public Radio, NBC Nightly News, NBC’s Today Show, NPR, New York Public Radio, the Associated Press, Modern Healthcare, TIME, The Wall Street Journal, The Washington Post and The Washington Times, among others.