

**Recommendation for Complete Electronic Health Records and  
Patient Privacy Protection in the Stimulus Bill**

January 15, 2009

Dear Members of the House and Senate:

As you consider investments in health information technology in the American Recovery and Reinvestment Act of 2009, we urge you to use the standards and priorities described below. These expenditures should be tied as much as possible to the development of systems that can successfully support the improvements in the quality and efficiency of health care we all desire. We have two key goals: (1) around the clock availability of a comprehensive and secure electronic health record (EHR) for each patient and his or her health care professionals and (2) protection of each patient's privacy through informed consent, transparency in the uses of each patient's information, and the development of ways for patients to implement their privacy preferences.

The standards we suggest will enable third party organizations to act on behalf of patients to assemble a comprehensive version of their records. Patients will control a comprehensive copy of their own medical record data and also have control over who has access to which portions of that copy. Patients can also use the information in their records for prevention and wellness. They can give health care professionals and third parties access to a comprehensive compilation of their records, or if the patient prefers, the minimally necessary information for a specific use.

The types of third parties that can give patients access to a comprehensive EHR are health record banks and trusts, personal health record vendors, health plans, and regional health information organizations, all of which are players in the field known as health information exchange. Patients would voluntarily choose to utilize one of these organizations based on their services. All of these organizations have a stake in reducing the barriers to patient acceptance and provider adoption of electronic health records because they succeed when more data is shared electronically. Additional public assistance will likely be needed, however, to help disabled patients, patients with chronic diseases, and patients and providers in underserved and rural areas achieve these same goals. Such assistance could also help reduce disparities in health care outcomes by deploying EHRs to help bridge language and cultural divides.

**Standards for Electronic Health Records Funding**

By the term EHR, we mean a digital collection of a patient's medical history including items such as diagnosed medical conditions, prescribed medications, vital signs, immunizations, lab results, and personal characteristics like age and weight.

All EHR systems supported with public funds must fulfill a patient's request for an electronic copy of all or part of their medical records, including audit trails and subsequent updates. The copy would be transmitted to the patient or a patient-designated third party. Copies and updates of EHR data must be made available within 24 hours, absent exceptional circumstances, at no

charge to patients or third parties, and should be available for sharing only with the informed consent of the patient.

Where the medical record information that the patient requests is textual, the copy must be in human-readable text, formatted at a minimum using either extensible markup language (XML) or PDF with data types and formats that are recommended and maintained by the National Institute of Standards and Technology in consultation with existing standards development organizations (see attachment). Copies of images and other non-textual medical record information would be handled using existing standards

The specific objective behind this standard for a patient copy of EHR information is to provide patients and, with a patient's explicit consent, the patient's providers, with both human and machine-readable textual representations of his or her comprehensive electronic medical record.

Publicly supported EHR systems should also provide a reliable process for authentication of the identity of all their users and an audit trail of all events including all disclosures of a patient's records.

Funding for EHR systems for underserved, safety net providers, and those with disabilities should be a priority, as should funding for organizations to educate underserved, rural populations, and those with disabilities about the use of health information technology and to help them use that technology.

#### Priorities for Funding Health Information Exchange

Health information exchange (HIE) is the movement of patients' health care information electronically across disparate systems while preserving the meaning of the information.

Funding for organizations that undertake HIE for patients should be prioritized according to how well they can achieve, and over time in fact do achieve, the following goals:

- The availability to patients and healthcare providers, around the clock, of XML outputs with informed patient consent, from the EHR systems of all the providers to the populations served by the HIE organization. A personal health record is one way for an HIE to provide such availability.
- The availability to patients of an audit trail that records all events in a patient's compiled HIE-EHR account in an easily understandable and searchable format.
- Reliable authentication of the identity of all users of the HIE organization;
- Service by the HIE organization to safety net providers, underserved populations, to those with disabilities; and
- A sustainable financing model to ensure that it can continue to provide its services to patients and providers alike.

We do not intend these standards and priorities to exclude other considerations in funding a wide variety of possible health information technology initiatives, but rather they are a strategy to achieve a comprehensive electronic health record for patients and to protect their privacy.

We respectfully request that you adopt this recommendation.

Sincerely,

**American Academy of Family Physicians**

**American College of Cardiology**

**Cerner Corporation**

**Greater Ocala Health Information Trust,  
Inc.**

**Health Record Banking Alliance**

**HFN, Inc.**

**Information Technology and Innovation  
Foundation**

**Louisville Health Information Exchange,  
Inc.**

**National Alliance for Hispanic Health**

**Patient Command, Inc.**

**Progressive Policy Institute**

**Secure Services Corp.**

**Self-Insurance Institute of America**

**You Take Control, Inc.**

## Attachment: Background on a Standard for Human Readable Copies of Electronic Health Record Data

The creation of a set of common standards for interoperable electronic health records continues to be a major challenge in health information technology. Examples of organizations currently working on this task include Health Level 7 (HL7), ASTM International, the International Health Terminology Standards Development Organization (IHTSDO), National Council on Prescription Drug Programs (NCPDP), the Health Information Technology Standards Panel (HITSP), and the Certification Commission for Health Information Technology (CCHIT). Standards developed by or vetted by these organizations are critical for interchanging digitized information between EHR systems, but none of them is ready to produce human readable copies of EHR information.

An XML format for patients' copies of EHR data would allow non-standard EHR systems to export patient data in a comprehensible form. XML is a free, non-proprietary standard widely used in commerce and industry, as well as by federal agencies and both houses of Congress. (See <http://www.usgovxml.com/>, <http://xml.house.gov/>, and [http://www.senate.gov/legislative/Public\\_Disclosure/database\\_download.htm](http://www.senate.gov/legislative/Public_Disclosure/database_download.htm).) XML is widely accepted as a way to format documents so they can be available via multiple computer systems. Another example of a widely used text standard is Adobe's PDF files. Although it is a proprietary standard, it may also be helpful in certain circumstances such as embedding graphics, images, and digital signatures to prove the authenticity of a copy.

XML or PDF files alone are not a standard for "structured data" that – if it existed – would allow legacy systems and new medical record computer systems to exchange health record data in a uniform, interoperable fashion. XML allows EHR vendors to export patient data as text, regardless of the format the EHR system uses. XML can also convey structured data when it is part of a more detailed health information standard such as HL7 version 3.

In creating an XML output for exporting patient data, EHR vendors would simply need to create a label (an XML tag) for each type of text data. Neither the data fields nor the labels for the data would need to conform to a standard. But every EHR vendor would have to register its data labels and any updates to the labels, with a public repository at the National Institute for Standards and Technology. Health information exchanges and others could then use these data labels to interpret the XML document output from each EHR vendor's system.

For example, one vendor might choose to label blood pressure data as "BP" and another might use "bldpress." The difference would not matter as long as the vendor made the meaning clear to NIST and consequently to HIEs and other recipients.

To facilitate some degree of uniformity, however, Congress should require NIST to create and maintain a set of recommended (best-practice) data labels for this purpose. NIST would use the updates of data labels sent to the public repository to maintain the correspondence between vendor-defined data fields labels and the NIST recommendations. The ASTM International Continuity of Care Record and the HL7 standard for a continuity of care document are examples of emerging standard sets of data labels using XML, respectively.

In summary, under this proposal, NIST would not develop new technology, a new standard for structured data or structured data interchange, or anything that would require expensive rewriting of

existing EHR systems. Rather, NIST would use existing XML standards for tagging English text so that it can be exchanged in human-readable form under patients' control.