
PART 1

National Health Surveillance

by Twila Brase*

SUMMARY: The Economic Stimulus bill (H.R.1)¹ is set to establish and fund a national health surveillance system—a national system for monitoring and tracking patients and doctors. The system will enable unconsented research on the American public and nationwide imposition of health care rationing.

Part 1:
National Health Surveillance

Following on President Bush’s 2004 executive order to create a national health information infrastructure, the Stimulus bill is poised to require computerization of all medical records.

One Linked Record: Every citizens will have a single, fully linked, fully trackable, comprehensive online medical record readily accessible to more than 600,000 entities, including government overseers.

Sale of Patient Data: H.R.1 will permit the buying and selling of private patient data for various reasons including research and government health surveillance activities.

Part 2: Science-Based Rationing
Part 3: Research without Consent
Part 4: No Privacy; No Security
Part 5: Counting the Costs

National Health Surveillance System Ordered

On April 27, 2004, President George W. Bush called for “the development and nationwide implementation of an interoperable health information technology infrastructure...”

By executive order, President Bush also established the Office of the National Coordinator for Health Information Technology (ONCHIT) within the U.S. Department of Health and Human Services (HHS).¹

ONCHIT was established to set a national vision for an online electronic medical records infrastructure. ONCHIT’s 2008 budget was \$61.3 million.²

To implement the order, the American Health Information Community (AHIC), a national four-committee structure of appointees, was established.³

¹ U.S. Senate version, as passed February 10, 2009.

“ Big Brother” Law

Now, five years after the 2004 executive order, President Barack Obama and the U.S. Congress are set to require the creation and imposition of a “nationwide health information technology infrastructure.” (p. 235)

The legislation will also make ONCHIT a permanent federal agency with sweeping powers over the establishment and use of the data system.

The U.S. House of Representatives

29% - number of respondents who had read or heard about proposed nationwide system of patient electronic medical records.

(2005 Harris Poll)

passed H.R. 1, the American Recovery and Reinvestment Act on January 28, 2009—the Economic Stimulus bill.

The vote was 244 to 188. On February 10, 2009, the Senate passed an amended version of H.R.1 with a vote of 61 to 37.

The Senate bill included a 141-page section called the “Health Information Technology for Economic and Clinical Health Act or the “HITECH Act.”(p. 230)

On February 11, 2009, the House and Senate reached agreement on the \$789 billion stimulus bill,⁴ which includes funding for health information technology and the establishment of a national health IT infrastructure.⁵

If the bill is signed into law, as is expected, by 2014, every citizen will be required to have a single comprehensive, fully-linked, fully trackable, online electronic medical record.

Physicians and others who fail to comply with the online electronic medical record mandate will receive *reduced* Medicare payments beginning in 2015.⁶

No Consent Required

Patients have a long-standing right to privacy. The right is enshrined in the constitution and the Hippocratic Oath. Patients also prize their medical privacy. (see Part 4).

Yet these digitized patient records will be “more detailed, more centralized, more permanent, and more easily-transmissible” than paper records.⁷

Furthermore, no patient consent is required, and public perception notwithstanding, the HIPAA “privacy” Rule does **not** protect privacy.⁸

HIPAA is a *data disclosure* rule, allowing more than 600,000 entities access to private patient data (online and offline) without the patient’s knowledge or consent.

Thus, the economic stimulus bill does not protect medical privacy or require patient consent for disclosure, access, data sharing, use, or dissemination.

One Linked Medical Record

The economic stimulus bill requires that there be “an electronic health record for each person in the United States by 2014.”

This means a single record for each patient, accessible around the country by every doctor, clinic, and hospital. Every

incident, every illness, every mistatement, every confession, every recorded word online and available.

The record must be a “certified electronic health record.” This computerized record must be compliant with government standards.

***Every
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Thus, the patient’s medical record must be compliant with, and linkable with—the proposed national health surveillance system.

When fully implemented, more than 300 million Americans will have a single comprehensive medical record online and readily available to government and others authorized with access under the HIPAA rule.

National Data Collection Tool

The nationalized online medical record must be able to collect data on individuals, including race, ethnicity, language and gender. (p. 249) It must also be able to report “quality” data on doctors. (see forthcoming Part 2)

It must also allow use of “clinical decision support”—software that displays national treatment protocols, various patient reminders and alerts on the computer screen during care of patients (p. 234)

Sweeping access to patient data is proposed by the economic stimulus bill. Beyond treatment, the new Health IT Policy Committee will be allowed to

consider using the national health surveillance system for:

- “The collection of quality data and public reporting;
- Biosurveillance and public health [involving individual records];
- Medical and clinical research; and
- Drug safety.” (p. 250)

In short, the proposed nationwide health information technology infrastructure will be used not only for national health surveillance and tracking, but also to conduct various research projects using individual patient data. (see forthcoming Part 3)

Data for Sale

The bill specifically allows the buying and selling of patient data. (p. 339) While it has a general prohibition on the sale of data without patient authorization, there are six gaping exceptions for purposes including:

1. Research and public health activities
2. Treatment of an individual—if the Secretary of HHS writes rules to prevent such data from misuse.
3. Purposes “otherwise determined by the Secretary in regulations to be similarly necessary and appropriate.”

To Protect American Citizens

To protect the confidential patient-doctor relationship, the privacy, patient, and data property rights of patients, and the security, accuracy, and confidentiality of

the patient medical records of all Americans, the following proposals should be considered:

- Consent for Online Electronic Medical Records: Require separate, written, informed opt-in patient consent for online storage, access, and transfer of electronic medical records and private personal health information.
- Consent for Research and Pay-for-Performance: Require opt-in, written informed consent for use of patient medical records data for treatment-influencing “pay-for-performance” initiatives, and medical, genetic, population health, health services and other research.
- Ownership: Secure patient ownership rights for medical record information.
- Civil Rights: Prohibit government access to patient data without informed written patient consent.
- Transparency: Provide patient access to a full accounting of all disclosures of their personal health information—paper or electronic—including disclosure to and use by state and federal government agencies.
- State Preemption: Maintain state’s rights (preemption) for medical privacy as required by the 1996 HIPAA law and the federal HIPAA privacy rule, thus protecting the right of state legislators to enact stronger, more patient-protecting laws.

ENDNOTES

¹ “Executive Order: Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator.” Office of the White House. April 27, 2004, <http://www.whitehouse.gov/news/releases/2004/04/20040427-4.html>.

² “White House seeks ONCHIT funding increase.” John Moore and Peter Buxbaum. *GovernmentHealthIT*. February 4, 2008.

³ “Office of the National Coordinator: Mission,” Office of the Secretary, undated, <http://www.os.hhs.gov/healthit/nc/mission/>.

⁴ “Congress Reaches Deal on \$789 Billion Stimulus Plan.” Breaking News Alert. *The New York Times*. 2/11/2009, 3:28 PM ET.

⁵ “House OKs huge health IT boost in stimulus bill,” Nancy Ferris, *GovernmentHealthIT*, January 29, 2009.

⁶ “Senate Passes Economic Stimulus Bill With Health Care Provisions.” Barbara Kram, *DOTMED NEWS*. February 11, 2009.

⁷ “Building Privacy by Design In Health Data Systems.” Dr. Alan F. Westin and Vivian van Gelder. Center for Social and Legal Research. August 2005.

⁸ Title 45, Federal Code of Regulations.