



January 21, 2009

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives

The Honorable Charles Rangel
Chairman
Committee on Ways and Means
U.S. House of Representatives

The Honorable Dave Camp
Ranking Member
Committee on Ways and Means
U.S. House of Representatives

The Honorable Henry Waxman
Chairman
Committee on Energy & Commerce
U.S. House of Representatives

The Honorable Joe Barton
Ranking Member
Committee on Energy &
Commerce
U.S. House of Representatives

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TREASURER

On behalf of the ACLU's more than half a million members and activists, and 54 affiliates nationwide, we write in support of the privacy provisions included in the Health Information Technology for Economic and Clinical Health ("HITECH") Act. These privacy provisions must be enacted without passage of weakening amendments to realize President Obama's vision of implementing a nationwide, interoperable electronic medical record system. Without the privacy provisions proposed in the HITECH Act, Americans will fear justifiably that their most private, personally identifiable information concerning their medical histories and conditions will be available to prying eyes.

Past experiences and recent studies show that if the confidentiality of electronic medical records is not guaranteed, a number of unfortunate consequences might occur, such as:

- An employer, after inappropriately reviewing electronic medical records, deciding not to hire a candidate for a job because either the candidate or his or her family is relatively expensive to insure¹;
- Data brokers buying up pharmaceutical and medical records of millions of patients and selling them to any willing buyer²;

¹ Thirty five percent of Fortune 500 companies admitted to reviewing job candidates' health records before making hiring decisions. 65 Fed. Reg. 82,467.

² See, e.g., *IMS v. Ayotte*, Case No. 07-1945, (First Cir. Nov. 11, 2008), upholding New Hampshire's law prohibiting the sale of certain pharmacy records of patients.

- Pharmaceutical companies sending invasive marketing solicitations to induce patients to switch to the companies' prescription medicines instead of those prescribed by their doctor³;
- Employees snooping on neighbors', friends' and former love interests' medical records; and
- Uninsured individuals committing medical identity theft by impersonating insured patients whose records they have snooped on in order to obtain treatment.

Consequently, it is essential for Americans' privacy that Congress swiftly enact the HITECH Act and defend it against amendments intended to weaken or gut its privacy protections.

The ACLU highlights the following provisions that are included in the HITECH Act that must be enacted into law:

- A prohibition on the sale of medical records;
- Requirements that systems permit the segmentation of records to compartmentalize information. This is particularly important for information that has been used to stigmatize patients in the past such as psychiatric or other mental health treatment and counseling, use of birth control or testing for sexually transmitted diseases, and other conditions or genetic predispositions that have no bearing on a doctor's evaluation, diagnosis and treatment for a wholly unrelated condition;
- Mandates for audit trails to help companies and patients determine whether patients' records have been inappropriately accessed, and if, so, by whom;
- Seats on advisory bodies dedicated to not-for-profit, privacy and data security experts;
- Automatic imposition of regulatory fines for actions constituting violations of the law that are deemed to have occurred through willful neglect; and
- Enforcement of violations of the Act by the Attorney General and/or U.S. Federal Trade Commission.

These provisions, as a whole, constitute a nearly comprehensive data privacy scheme that will, if enacted into law, engender a culture and require a series of databases that work to protect each patient's most sensitive medical information.

While the bill contains important privacy provisions, the ACLU recommends the addition of several additional protections to safeguard patients' information. First, most software now routinely permits encryption of sensitive data. Congress should mandate the encryption of personally identifiable information while in electronic storage and in transit. Second, the provisions prohibiting the sale of records are strong, and wisely prohibit

the offering of "direct or indirect remuneration," but clever corporate lawyers might find loopholes to exploit if other types of exchanges, trades or sharing of data are not prohibited as well. Third, we believe that Congress should not permit patients to authorize the sale of their data because companies will offer patients some small remuneration and/or benefit that will induce patients unwisely to authorize such sales. Fourth, requirements that electronic medical

³ See, e.g., www.alarmedaboutcvscaremark.org.

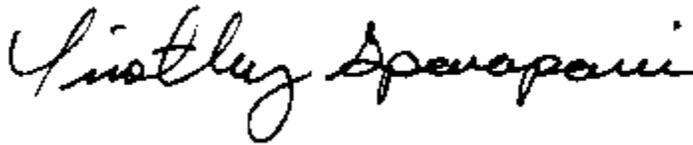
records systems provide the capacity for audit trails to review unwarranted viewing and accessing are delayed too far into the future. The technological capability exists now for audit trails to be required, and retrofitting systems in the future that were sold prior to the deadline for compliance will be unnecessarily expensive.

Although we would urge more, the HITECH Act is a strong, privacy-protective bill that deserves congressional support. The ACLU urges Congress to enact the HITECH Act, as introduced, without passage of amendments that would unravel this carefully constructed package of protections.

Sincerely,

A handwritten signature in black ink, appearing to read 'Caroline Fredrickson', written in a cursive style.

Caroline Fredrickson
Director, Washington Legislative Office

A handwritten signature in black ink, appearing to read 'Timothy Sparapani', written in a cursive style.

Timothy Sparapani
Senior Legislative Counsel