

May 15, 2008

The Honorable Patrick J. Leahy  
Chairman  
Senate Judiciary Committee  
United States Senate  
Washington, DC 20510

Dear Chairman Leahy:

As members of the Consumer Partnership for e-Health, a non-partisan group of consumer, labor, patient, and research organizations working to improve health care quality through expanded use of information technology, we are writing to applaud your leadership on protecting the privacy and security of Americans' personal information. We appreciate the opportunity to comment on your most recent proposed amendment to the Wired for Health Care Quality Act, S.1693, and believe it represents an important step in the development of a privacy and security framework to guide the exchange of personal health information. By setting forth incremental, workable privacy solutions that build on current law, you have laid a foundation upon which a more comprehensive privacy and security framework can be built.

We believe that health information technology and exchange (HIT/HIE) are critical underpinnings of a more patient-centered health care system. It can facilitate better coordination of care regardless of patient location, encourage higher quality and more efficient care, increase system transparency, and encourage patients' active engagement in health care decision-making. At the same time, such a system raises serious concerns among consumers about personal privacy, data security, and the potential misuse of their information. And while an interoperable system of electronic health information holds great promise, the many possible benefits will not be realized unless appropriate policy measures are established up front.

Your amendment takes some important steps toward achieving an effective balance between promoting HIT/HIE and systemic safeguards. These steps are consistent with the Consumer Principles for Health Information Technology in the following ways:

- **Promoting individuals' access to their health information** by providing individuals with the right to receive their health information in an electronic format, when it is available.
- **Helping consumers to have better knowledge and understanding about how their health information may be used** by tasking the Secretary of HHS to develop a model, consumer-friendly summary privacy notice.
- **Granting individuals more control over whether and how their health information is shared** by tightening the definition of "marketing" under the current HIPAA Privacy Rule so that consumers have the right to consent to uses of their health information for marketing.
- **Protecting the privacy, security, and confidentiality of an individual's health information** by making the Secretary responsible for developing

standards and protections for notification of privacy and security breaches that involve access to or disclosure of personal health information for unauthorized purposes. In addition, the amendment requires the Secretary to recommend appropriate privacy and security protections for personal health records.

- **Ensuring transparency and accountability for how various entities handle and use the information entrusted to them** by requiring HHS to report annually to Congress the number of HIPAA related complaints it receives and how they are resolved, thereby increasing accountability under the current HIPAA Privacy Rule. The amendment also calls for a GAO study of the effectiveness of HHS in implementing the health privacy provisions of Wired, with the goal of gaining insight into how best to continue strengthening privacy.

We also applaud you for recognizing that in the emerging landscape of networked health information, relying solely on a consent process to protect individuals' privacy is insufficient. Put simply, consent alone places all responsibility for privacy protection in the hands of patients and consumers and absolves other stakeholders from taking an active role in protecting patient privacy. In circumstances when a consumer is seeking medical attention, such unilateral responsibility could be forced upon them at a time when they are least capable of advocating on their own behalf. Sound policies must ensure that the systems and processes developed for the purpose of HIT/HIE enable consumer engagement AND hold all those with access to personal health information accountable for how this information is handled and used. Truly consumer-friendly policies will provide a comprehensive framework of privacy and security safeguards to guide e-Health implementation even as we find new ways to aggregate and use health care information and data to power health care system improvement.

Thank you for your strong commitment to ensuring that privacy and security are built into the rapidly evolving electronic health care environment. Your leadership is vital to promoting implementation and use of HIT/HIE, which is essential for improving the quality of health care. We look forward to working with you on these critical issues.

Sincerely,

AARP  
AFL-CIO  
American Federation of State County and Municipal Employees (AFSCME)  
Center for Medical Consumers  
Childbirth Connection  
Consumers Union  
Department for Professional Employees, AFL-CIO  
Health Care for All  
National Consumers League  
National Partnership for Women & Families  
SEIU  
Title II Community AIDS National Network

Members of the Consumer Partnership for e-Health