



June 1, 2009

Federal Trade Commission
Office of the Secretary
Room H-135 (Annex M)
600 Pennsylvania Avenue, N.W.
Washington, D.C. 20580.

**Comment to the Federal Trade Commission RE: Health Breach Notification
Rulemaking, Project No. R911002**

Dear Secretary and Commission:

The American Association of People with Disabilities (AAPD) is pleased to submit a few brief comments and recommendations in regard to your notice about health record breach notification.

AAPD is the largest national nonprofit cross-disability member organization in the United States, dedicated to ensuring economic self-sufficiency and political empowerment for the more than 50 million Americans with disabilities. AAPD works in coalition with other disability organizations for the full implementation and enforcement of disability nondiscrimination laws, particularly the Americans with Disabilities Act (ADA) of 1990 and the Rehabilitation Act of 1973. We also work in coalition with other organizations and entities on various non-disability related policy issues.

The Recovery Act recognizes that there are new types of web-based entities that collect consumers' health information. We note that some vendors of personal health records and online applications that interact with such personal health records are not subject to the privacy and security requirements of the Health Insurance Portability and Accountability Act ("HIPAA"). For such entities, the Recovery Act requires the Department of Health and Human Services (HHS) to study, in consultation with the FTC, potential privacy, security, and breach notification requirements and submit a report to Congress containing recommendations within one year of enactment of the Recovery Act. Until Congress enacts new legislation implementing any recommendations contained in the HHS/FTC report, the Recovery Act contains temporary requirements, to be enforced by the FTC, that such entities notify customers in the event of a security breach. The proposed rule implements these requirements. **Our Comments follow.**

AAPD Comments Re Proposed Rule

AAPD supports the interim proposed rule that says vendors of personal health-record systems must notify the FTC and "each individual who is a citizen or resident of the United

States whose unsecured, PHR identifiable health information” was acquired by an unauthorized person as a result of such a breach of security.” We would support this requirement in a final rule.

AAPD also supports the rule in the Recovery Act that seeks to place vendors of certain personal health-record systems contracted for by providers, payers and other so-called “covered entities” under the security and privacy rules promulgated in accordance to the Health Insurance Portability and Accountability Act of 1996. We would support this requirement in a final rule.

We believe that Breach Notices are critical to the public’s trust in health information technology systems. Breach notices will inform consumers with disabilities which vendors and systems to avoid and which offer the highest level of protection for sensitive health data. It is essential that HHS ensure that breaches are reported in all situations the average person considers to be a privacy or security breach. Breach notices must apply in a comprehensive rather than a narrow or selective way.

AAPD Recommendations for the Final Rule

In standards development:

1. As a principle, ensure that technologies associated with medical records are designed and developed so that people with disabilities (including but not limited to vision, speech, and hearing disabilities) enjoy the same privacy and functionally equivalent access and usability of their medical records as persons without disabilities.

AAPD believes far too little attention has been paid to user interfaces for medical records and that developers of health information systems have failed or otherwise minimized the importance of the need to ensure that people with disabilities will have the same usability and accessibility when using health information technology systems that others will enjoy. This means that attention should be paid to both the electronic interface to access records and to the formats for breach notifications – whether electronic, print or by other means.

There are millions of people who are, in effect, print-disabled: that is, people who cannot effectively read print because of a visual, physical, perceptual, developmental, intellectual/cognitive, or learning disability.¹ Breach notifications should therefore be available also in formats other than print.

2. AAPD encourages HHS to include Guidance on the form of breach notification and include requirements that breach notices be available in alternate formats such as large font, Braille and audiotape, or other means, at the request of the consumer affected and their patient or medically-related record. Registering these preferences should be built in to electronic record keeping systems.

Furthermore, such notifications should be written in plain language and easily understood by an average member of the public; this should also be a requirement in breach notification.

¹ See more at <http://www.readingrights.org/node/128>, last accessed May 28, 2009.

In regard to **state breach notification laws**:

3. Covered entities or business associates should send multiple notices to an individual upon discovery of a single breach.

AAPD asserts that there should be redundancy in breach notification. It is easy for consumers to miss notifications, misunderstand notifications or otherwise fail to recognize the content of a notification in these information-laden “junk mail” times. Further, for people with disabilities, one notification may be insufficient for any number of reasons, particularly if it is not available in an alternate format, such as for those with vision loss. And, for persons with intellectual disabilities, they may first need to consult with another person on the meaning of the notification and what steps may need to be taken.

Redundancy of contact about a breach would be helpful also in some circumstances such as where a person with a disability lives in congregate settings where mail may be slow or misdirected, when caregivers or representatives may routinely handle business affairs on a monthly or biweekly basis, when Post Office Boxes are used due to transitory life-styles, or when a person may live in multiple locations (home, disability setting, rehabilitation hospital or other treatment location). Any of these circumstances could lead to delay of receipt of a breach notification. In such situations, redundancy of contact about a breach is a plus as it increases the chance the consumer with a disability will learn of the breach and be able to take any necessary steps to stanch any likely damage or prompt them to have someone else take the necessary steps.

AAPD appreciates this opportunity to offer input on these topics that are of significance to the millions of people with disabilities in the U.S. who look to their federal government to ensure that their health information is accessible to and usable by them, that it remains secure, and they have the same functionality as everyone else.

Sincerely,

Jenifer Simpson
Senior Director, Government Affairs
Tel: (202) 521-4310
Email JSimpson@aapd.com

AAPD viewpoints on health information technology at
<http://www.aapd.com/TTPI/healthtech.html>

American Association of People with Disabilities
1629 K Street NW, Suite 503 • Washington, DC 20006
phone 202-457-0046 (V/TTY) • 800-840-8844 (V/TTY) • fax 202-457-0473 • www.aapd.com