



WORLD PRIVACY FORUM

December 18, 2008

The Honorable Susan Ness  
Professor Peter Swire  
Professor Philip Weiser  
Presidential Transition Team  
Washington, DC 20270

Dear Commissioner Ness, Professor Swire, and Professor Weiser,

Thank you for requesting our comments regarding priorities for the Federal Trade Commission.

We want to call your attention to an increasing amount of unregulated and identifiable consumer health care data, and what that means for the FTC going forward. We also point to the need for greater transparency in the digital environment.

**I. Health care data held outside of HIPAA protections needs increased privacy protection and FTC attention**

This week, the HHS Office of Civil Rights issued guidance that underscored the point that a considerable amount health care information, including information in some medical files, is not protected by HIPAA because it is held by an entity not covered by HIPAA. Also this week, HHS released its privacy and security framework for health information held outside of HIPAA. In its framework, HHS proposed a self-regulatory regime for protecting health data held by non-HIPAA covered entities. In this proposal, personal health records would be protected by voluntary policies, leaving a major part of the partially-implemented nationwide health information exchange system subject only to enforcement by the FTC.

For example, to protect the privacy of patient records uploaded to personal health record web sites such as Google Health, Microsoft Health Vault, and other entities not covered under HIPAA, HHS proposed a model privacy policy that could be voluntarily adopted and posted on the PHR vendors' web sites.

The privacy of highly sensitive consumer health information held outside of HIPAA should be a top priority for the FTC. There is a real likelihood that consumers could unwittingly allow their health information to flow from these non-provider sources into the hands of data brokers and marketers without legal protection. The result could greatly



undermine the health and privacy interests of consumers. The effect on insurability, employment, credit, and other major activities could be significant.

Before the Fair Credit Reporting Act, an unregulated industry of vendors whose files affected or determined how individuals could function in society had run amok. With HHS encouraging the routine maintenance of unregulated health data outside of HIPAA, we could unwittingly recreate for health data what happened with credit data.

## **II. Medical identity theft will continue to grow as an issue; the FTC needs to own all forms of identity theft going forward**

We see evidence that medical identity theft will continue to grow and create problems for consumers and the entire health care system. Our research indicates that many medical identity theft victims are also victims of financial forms of identity theft. Carving up identity theft between HHS and the FTC does not make sense for the victims, nor is it efficient.

We think the FTC should have the authority to handle all forms of identity theft in its education, outreach, and other activities. It is crucial that the FTC have the authority to act as a central organizer for financial, medical and other forms of identity theft, so that consumers have a central place in government where they can go for help. As new forms of identity theft come to light, it will be important for at least one agency to be able to coordinate efforts among agencies. We would like to see the FTC, with its long expertise in identity theft, be this agency.

## **III. The FTC has a fresh opportunity to encourage and facilitate greater transparency for consumers engaging in the digital marketplace**

Today's consumers want to be able to operate online with a sense of trust. From purchasing music to tracking workouts to working with colleagues, consumers increasingly conduct their lives digitally.

Trust requires transparency, and true transparency is in short supply in the digital marketplace. Consumers already have the right to see their credit bureau reports and credit scores. In most states, consumers are also notified of data breaches of personal information. These are important rights, and access to this information benefits consumers.

The FTC has an opportunity to support and facilitate the next logical step forward. Consumers need expanded abilities to see the personally linked information that any company holds about them and to know the rules that protect their data against misuse, bankruptcy of the data processor, and other foreseeable activities that occur routinely in the marketplace.

Credit data is not the only type of data that requires FCRA-like Fair Information Practices. As consumer health data increasingly enters the unregulated information stream, along with cloud computing, social networking, and other online activities, transparency and privacy protections are going to become increasingly important to prevent consumer harm. Consumers need more help from the FTC.



Respectfully submitted,

/s

Pam Dixon

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