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PREPARED STATEMENT OF

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DEPARTMENT OF HEALTH AND HUMAN SERVICES OFFICE OF  
THE NATIONAL COORDINATOR FOR HEALTH INFORMATION  
TECHNOLOGY

PHR ROUNDTABLE

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## **THE REAL PROBLEM IS NOT “PRIVACY AND SECURITY,” BUT ACCESS TO INFORMATION**

Obtaining access to a copy of a patient’s medical information today is at best difficult and time consuming – it is about to get much worse without active HHS and FTC intervention.

The headline on the front page of the Sunday, November 21<sup>st</sup>, *New York Times* read “AS HEALTH LAW SPURS MERGERS, RISKS ARE SEEN.” Recently, a number of major newspapers, from the *New York Times* to the *Washington Post*, and numerous health care journals have run stories and commentary predicting the new enacted health reform bill will reduce competition. Jon Leibowitz, Chairman of the Federal Trade Commission, echoed the same sentiment as he publicly worried that the new health reform bill could stifle competition.

This has not escaped the attention of health plans and providers across the country. Small to medium-sized health plans are nervously looking over their shoulders and worrying that large national health plans will take them over or drive them out of business. Many healthcare providers will face sleepless nights as the new health delivery models envisaged by the health reform bill, such as accountable care organizations, will, by design, consolidate the delivery of health care services in the hands of fewer providers.

What does this mean for consumers of health care, the patient, and personal health records or PHRs? It means that the consumers of health care will have fewer choices. It means that patients will have a more difficult time getting good information or gaining access to their own medical records in a timely or meaningful way. It most certainly means that larger and more powerful provider and health plan conglomerates will hold patients medical information hostage.

## **GIVING PATIENTS ACCESS TO THEIR OWN MEDICAL INFORMATION IS NOT JUST A GOOD IDEA, IT’S THE LAW**

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 and The American Recovery and Reinvestment Act (ARRA) of 2009 give patients the right to receive copies of their medical information. ARRA gives patients the right to receive electronic copies of their medical information. The statute also allows patients to instruct health plans and providers to send this information to a PHR service, like Dossia. It is the law.

## **HEALTH CARE COMPANIES LOCK IN CUSTOMERS BY HOLDING PATIENT INFORMATION HOSTAGE**

Giving patients the right to receive their own medical information may be both a good idea and the law, but some health plans and providers have other ideas. Over the last two years, both large employer health benefit groups and Personal Health Record services like Dossia have seen health plans, providers and others block a patient’s access to his or her

medical information in the name of privacy and security. Many health plans and providers tell us that sending a patient's information to a PHR service like Dossia would create unacceptable risks. They hold on to this position even after the patient asks the health plan or provider to send the information. They hold on to this position even after the health plan or providers' lawyers review Dossia's very strict standards regarding the receipt and housing of protected information.

After lengthy and time-consuming negotiations with health plans and providers, it becomes clear that the issue is not about risk or liability but about trapping customers. Many medical products and procedures are commodities and a patient with access to his or her own medical information can make better and more informed decisions about medical services... and that might mean choosing another health plan or provider.

They would rather withhold the information than compete on service, price and quality.

In this context, the term "providers" includes institutional providers like hospitals and health professionals (e.g., physicians and PAs) but also medical test laboratories, large chain drug stores and mail order pharmacies - particularly those that operate pharmaceutical benefit management plans (PBMs), and imaging facilities.

### **PROTECTING A PATIENT'S MEDICAL INFORMATION AND A PATIENT'S ACCESS TO HIS OR HER MEDICAL INFORMATION ARE NOT MUTUALLY EXCLUSIVE**

Dossia believes the obligation to protect a patient's medical information is not negotiable. It is an absolute responsibility not a voluntary effort. But protecting the privacy of a patient's medical information and protecting a patient's access to his or her medical information are not mutually exclusive. They only appear to be mutually exclusive when a health plan, provider, or other health business puts their own organization's interests before the needs of the patient.

### **THE HHS AND FTC HAVE A RESPONSIBILITY**

The Department of Health and Human Services (HHS) and the Federal Trade Commission (FTC) has a two-fold responsibility. The first is to establish policies and standards governing the privacy rights of patients and the responsibility of those in possession of protected information to keep protected information confidential. The second is to ensure health care companies do not stifle competition by spuriously waving the banner of privacy

### **DOSSIA'S PRIVACY AND SECURITY STANDARDS SHOULD BE THE NORM**

Dossia privacy policies and information security systems meet or exceed all of the HIPAA and other federal standards, as well as industry standards. Dossia stores personal health record information in an encrypted format and, in the very unlikely event of a breach, intruders would only have access to unusable encrypted data.

We at Dossia believe that a patient should control the sharing of his or her personal health record. Neither Dossia, employers, providers, spouses, and in many instances parents have access to the patient's personal health record unless the patient explicitly grants access. In addition, Dossia has very rigorous standards and processes in place for validating any request to grant others access to a patient's personal health record.

Dossia does not "mine" information from personal health records; we do not advertise nor do we create "links" to other health related websites based on the information entered into a personal health record.

## **RECOMMENDATIONS**

- 1) HHS and the FTC should ensure there are stipulatory (or agreed upon) standards and expectations for maintaining medical data privacy that are followed by all players. Dossia believes that every PHR service should adopt the same privacy policies and rigorous security standards as Dossia.
- 2) HHS and the FTC should require that all health plans, providers and other health care services release the patient's information (at their request) to any PHR service meeting the same privacy policies and rigorous security standards as Dossia.
- 3) The FTC should prohibit health plans, providers and ancillary service entities from holding a patient's medical information hostage and deem those impeding the release of this information as engaging in anti-competitive behavior and subject to fine.

## **WHY DOSSIA**

Several years ago, a diverse group of large employers came together to discuss the problem of rapidly increasing health care costs amid stagnant quality improvements. These employers represented different sectors of our economy and their employees similarly reflected very different sectors of the labor market.

However, each of these employers had a common interest – slowing the increase in cost of health benefits to both employers and their employees by empowering employees to take greater control of their health and health care. Over the last five to ten years, each of these employers tried a variety of different approaches to contain rising health care costs – including many of the tools used by managed care companies, e.g., pre-approval of service, increased deductibles and co-payments. The results were mixed. These companies came to the realization that cutting benefits and increasing co-payments would generate savings in the short term, but did not address the fundamental reasons health care costs continue to increase more quickly than other costs. In the long term, cutting benefits or increasing co-payments and deductibles made employees unhappy and, in a few years, health care benefit cost increases returned to unsustainable levels.

Together these companies concluded that a healthy and informed workforce was the only way to slow the increase in health care benefit costs. Giving employees access to, and

control of, their own medical information in a useable and meaningful format was both an essential and a missing element in this process. These companies worked together to build a platform that would allow their employees to have all of their medical information housed in a safe, independent and secure environment. This platform became Dossia. Today the founders of Dossia offer all of their employees enrolled in their health benefits program the option of creating a personal health record through Dossia. Employers assume all of the cost of maintaining this system and employees have come to view the right to maintain a secure personal health record as a benefit of employment.

## **ADDENDUM**

### **PERSONAL HEALTH RECORDS AND FRAUD AND ABUSE**

Fraudulent billing and organized health care identity theft have become a multi-billion dollar business. The CEO of every health plan will tell you that tracking fraud is both difficult and time consuming. In many instances, by the time a health plan suspects fraud, the culprits are long gone and the plan is embroiled in the process of “pay and chase.” Numerous studies have shown that an informed patient is one of the best ways to deter fraud. Most patients are upset and angry when they learn that one of their health care providers fraudulently billed their health plan using their name or medical condition.

Unfortunately, the current system does not give patients the tools they need to detect fraud. The explanation of benefit statements, or EOBs, we all get from insurance companies are, at best, confusing and, more often than not, unreadable. To make matters worse, health plans send us one EOB for physician services, another EOB for the procedure, and a third for the institution.

A personal health record is the only comprehensive and usable record available to patients. On top of supporting better point-of-care physician decision-making, better care coordination, reduction in duplicate testing and procedures, and more informed consumer/patient decision-making, a PHR also provides both patients and health plans a real tool to fight fraudulent billing.