

Abstract for a call for Paper for ID360: The Global Forum on Identity

Foundations for enabling health information as an asset class

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The rapidly unfolding transition to online electronic medical record systems, laboratory and prescription reports, nursing home and home care clinical systems, telecare monitoring devices and personally controlled digital tracking devices such as pedometers, nutrition logs, and programmable exercise machines, has generated a tsunami of personal health data. This data holds great promise for increasing research and data needed to improve healthcare effectiveness in the US and globally, which may help to limit the spiraling costs associated with health services delivery. As well known, readily available electronic data can enable health and wellness service providers to access detailed information about an individual's health profile, personal and family history, habits and lifestyle, which can support efficient diagnosis and treatment based on a holistic perspective that allows for individualized therapy and more effective monitoring and timely intervention. Apart from this clinical value, however, the construction of very large "Big Data" repositories gathered from millions of individuals can enable better analysis of emerging clinical trends and possible identification of new emerging categories of disease as well as comparative efficacy of alternative treatments. At the same time, the ready availability of rich, high-quality data can empower individuals and their care givers to compare and contrast their personal situation with others, making personal health management social and health services consumers more informed and discerning. For instance, individuals will now have the ability to decide what personal data they would like to share with others for research or joint comparison of matters.

Constructing Big Data sets composed of personal health information presents a variety of unique technical, legal, and fiduciary challenges. First, source data for Big Data sets can come from a variety of locations and creators; integrating the data and cleansing it to provide a reliable and accurate picture is notoriously difficult. Second, on-line electronic health data must achieve levels of security and reliability that are unparalleled. The law requires that every data point have an unbroken chain of responsibility that can be reliably reconstructed on demand. More important, health data errors can have extreme consequences. Where data errors in financial data, for example, can impose financial costs and damage reputations, errors in health data can cost lives. The biggest challenge associated healthcare related data has been associated with the "authentication," matching personal identities with data sets, and with ensuring that this data is clinically reliable. Furthermore, having access to this level of deep-information about an individual exposes the potential of misuse of such information by a variety of consumers of such data.

Given the unique aspects of creation, maintenance and validation of healthcare data, the authors present a new approach for the establishing the basis for a new ***healthcare data asset class***. This new approach requires a framework where-in the individual and their service providers are in a collaborative engagement, via a double-click-authentication process, which ensures the accuracy and consistency of the healthcare data allowing them to extract greater value from the healthcare marketplace. In addition, personas created by individuals have to be seamlessly authenticated to a medical profile so

that accurate and meaning comparisons across groups can be made. Thus, by creating a market for healthcare data and reliable sources for verification, the healthcare data market could resemble a right comparable to an intellectual property right in which the owner has total control, the right to decide the use of their data and bring action against misappropriators. This process will give greater control to the individual and assist in creating better healthcare support and research, but the system must first find a way to assure that healthcare data entered into the systems is reliable and credible. This paper will examine the policy and privacy issues involved in creating this system and delineate a software system capable of providing such reliability and credibility.