Privacy and the Health Information Domain: Properties, Models and Unintended Results

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Introduction

Health privacy is not binary; it is difficult to find anyone who opposes the abstract concept of protecting personal health information. For a non-binary issue, however, the subject is remarkably controversial. This article identifies and explores three reasons for the continuing controversy. First, the article details how privacy is only one “property” of the broad and quite complex health information domain. Second, it describes the different models available to regulators seeking to protect patient information and the operational choices made by mature regional and national legal systems. Third, the article briefly notes some of the unexpected and occasionally unwelcome results that follow from applying these protective models to the health information domain.

The Health Information Domain

The traditional and somewhat Panglossian concept of patient privacy does not fit well with the modern health information domain. As it has with other information domains, technology has dramatically changed the way patient health information can be acquired, stored, aggregated, processed, accessed and distributed. More specifically, the social, economic, and, now even, security uses of health information are in almost continual tension with the domain’s more patient-oriented properties.

The health information domain has several key properties that extend beyond traditional confidentiality, which is inherent in the physician-patient relationship, into the modern realm which is data protection. Individually, they are privacy,
confidentiality, anonymity, access, unity (or comprehensiveness), security, integrity and quality.

**Privacy, Confidentiality & Anonymity**

Traditionally, privacy and confidentiality have been used interchangeably in discussions of health information. In fact, they have diverse functions and, frequently, quite different juridical underpinnings. Confidentiality places limits on disclosure, while privacy is functionally an antecedent to confidentiality, limiting data collection. Anonymity enhances privacy by frustrating the collection of personal identifiers.

**Access**

Access is not a difficult concept. In practice, however, it creates immense problems because of the sheer number of persons, processes and institutions asserting access needs or “rights.” The health information domain has long included the access property, establishing a multitude of public health and law enforcement exceptions to any privacy regime. Traditionally, public health provisions and those requiring access for judicial process were broadly stated. In contrast, some modern public health provisions, such as those designed to combat AIDS/HIV, encourage reporting by explicitly limiting the access property.

The most recent complication to the access property is the imperative to reduce medical and medication error. Regulators on both sides of the Atlantic have taken the position that reporting errors or publicly disseminating outcome data will encourage safer practices or, at least, increase consumer choice.

The access property is also being shaped by fundamental changes in the practice of medicine and shifts in the physician-patient relationship. Today, it is far more likely that a patient’s care will be shared between several providers, and each will require access to a comprehensive medical record. Equally, the respect for patient autonomy, particularly choice, and the responsibility for care that a patient now shares with her healthcare providers requires that a patient be given access to her own records.

**Unity**

The realities of modern healthcare and the evolving physician-patient relationship are changing our perception of the patient record just as they broadened the access