Designing an Information Accountability Framework for eHealth

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1. Introduction

Information privacy is a crucial aspect of eHealth. Appropriate privacy management measures are therefore essential for its success. However, traditional measures for privacy preservation such as rigid access controls (i.e., preventive measures) are not suitable to eHealth because of the specialized and information-intensive nature of healthcare itself, and the nature of the information. Healthcare professionals (HCP) require easy, unrestricted access to as much information as possible towards making well-informed decisions. On the other end of the scale however, consumers (i.e., patients) demand control over their health information and raise concerns for privacy arising from internal activities (i.e., information use by HCPs). A proper balance of these competing concerns is vital for the implementation of successful eHealth systems. Towards reaching this balance, we propose an information accountability framework (IAF) for eHealth systems.

Information accountability (IA) is an idea concerning the appropriate use and after-the-fact accountability for intentional misuse of information. It is expected that transparency and the presence of accountability mechanisms act as a deterrent for intentional misuse of information. eHealth systems that are built to follow the principles of IA are coined Accountable-eHealth (AeH) systems. Figure 1 depicts a scenario that highlights the role of IA in the eHealth domain. In the scenario, we see how consumers’ healthcare information might flow in the eHealth environment. The flow of information between the professional and public domains must be monitored by a mechanism to control the way in which the data is used by HCPs and to ensure the public of the security of their sensitive information. This mechanism can be implemented as an information accountability framework (IAF). The three main aspects of the IAF and their interrelationships are shown in Figure 2.

2. Information Accountability Framework

Applying IA to eHealth, we formulated an IAF that consists of three main aspects: social, technical and legal. The IAF is presented by providing supporting evidence for each component.

A. Social Aspects

To develop successful eHealth systems, it is important to understand how consumers perceive their capabilities, policies and procedures. For example, AeH systems enable healthcare information manipulation to be transparent to the consumers whilst allowing nominated HCPs to access healthcare information which they professionally judge is required to make a healthcare decisions despite the usage policies in place. To enforce accountability, the consumers are allowed to make...
inquiries about possible misuse of information from HCPs themselves. In order to measure the impact such characteristics would have on system adoption, we take a theoretical approach commonly used in information systems research. Along with previously developed factors of technology acceptance such as perceived usefulness, perceived ease of use, computer attitude and computer anxiety, we investigated the impact of IA characteristics by gauging the attitudes of future eHealth stakeholders. Our approach was twofold. We conducted two online surveys to measure the attitudes of future healthcare professionals and eHealth consumers in Australia. In the first survey, we measured the attitudes of future healthcare professionals towards AeH systems. The findings revealed that IA measures do not negatively influence the intention to use AeH systems. Quantitative and qualitative data obtained also revealed that the respondents support the use of IA in the eHealth domain as a means of balancing stakeholder requirements. In the second survey, we measured the attitudes of potential eHealth consumers towards AeH systems. Similar to previous results, the respondents’ attitudes towards IA in eHealth was supportive. As a result of this work we were able to develop and validate two empirical research models that can be used to identify the factors contributing to the perceived intention to use AeH systems. We expect to further validate these models with a wide range of user groups in the future.

B. Technical Aspects
The main technical barrier for AeH systems was the representation and manipulation of usage policies. As a novel solution to this problem we adopted Digital Rights Management (DRM). The Open Digital Rights Language (ODRL) is a DRM technology that is capable of representing a wide range of policy-based information. The semantics of ODRL falls neatly in line with the protocols designed for AeH systems. Instead of assigning usage policies to digital assets (i.e., EHR data items in our case), we assign usage policies to HCPs. This allows eHealth consumers to assign a wide range of usage policies to their preferred HCPs to having a default access policy assigned to each data type. This is appropriate to the eHealth domain because the same data type may have different sensitivity levels for different consumers. Although consumers are capable of defining usage policies, the involvement of a central healthcare authority guarantees that the required access levels are always given to the appropriate HCPs without hindering the consumers’ privacy requirements. With the use of a Web based prototype, we were able to successfully demonstrate the representation and management of usage policies in AeH systems.

C. Legal Aspects
Like any eHealth system, AeH systems also rely on appropriate legislation for the governance and regulatory mechanisms to be established. We conducted a case study of the Australian eHealth system and identified that in its current state, the Australian legal foundations are inadequate for implementing the regulatory mechanisms necessary for AeH systems to function as intended. In Australia, the Privacy Act 1988 (Cth) set forth the measures relating to information privacy issues. In order for AeH systems to operate effectively in the Australian context, issues such as mandatory data breach notification, information ownership, information access and use and methods of accountability (penalties for misuse) must be adequately addressed. However, with the imminent enactment of a general data breach notification law and other recommended changes to the Privacy Act, the foundations sufficient to support AeH systems are slowly being laid.

3. Conclusions
The findings of our research study revealed that IA can be successfully used to address the information privacy conundrum in the eHealth domain. The efforts resulted in an IAF and coined a new genre of eHealth systems; AeH systems. Three main dimensions of the IAF were investigated and the foundations were laid for AeH systems to be implemented, specifically in Australia. However, there is a long and exhilarating road ahead towards implementing AeH systems, as expected with any eHealth initiative.

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References
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