The Evil Side of Sharing Personal Health Information Online

Emergent Research Forum (ERF) Paper

Abstract

When joining a social network users are typically asked to register and supply their personal/private information. As part of the registration process, users must confirm that they have read the terms and conditions of site use, as well as the privacy policy for that particular social network. Do people actually read these documents, and do they really understand what they are consenting to? When it comes to sharing personal health conditions with others online, it is worth considering who will have access to this valuable, sensitive data and how it will be used in the future. This research aims to improve the form and accessibility of contractual information presented to users of Health Social Networks (HSNs), by looking at alternative ways to engage and communicate these details on registration. Taking a mixed methods approach, this research observes registration behaviours and questions users on their engagement with eConsent through HSNs. Our aim is to elucidate the challenges, risks and potential dangers associated with sharing personal health information (PHI) using HSNs. This research proposes a list of guidelines to better support user's decision making needs when choosing to register and providing personal health information to HSNs.

Keywords (Required)

eConsent, Privacy, Health Information, Health Social Networks.

Introduction

Health Social Networks (HSNs) offer users the potential to connect with others about health related data, sharing their experiences and learning from each other (Li 2013). If an individual registers on one of these HSNs, they typically have to provide their name, email address, health condition and identify common medications taken. Once registered they can continue to build their health profile. The positive aspects of connecting on these sites are that users can share their health experiences, learn from each other and feel connected to others with similar health issues (Wicks et al. 2010). In doing so, HSNs increase the users' knowledge and understanding of their health condition (ibid).

When registering on a HSN, users must confirm that they have read the terms and conditions of site use. Ideally when joining, people should check that they are happy with these conditions. HSNs registered in a specific jurisdiction are then governed by that country's data protection laws. For example in USA, the Health Insurance Portability and Accountability Act (HIPPA 1996) regulates PHI. Therefore, as a HSN user (registered in USA) you are signing up to the regulatory standards of the USA. Prior research has found that HSN users are not always happy about accepting the terms and conditions and privacy policies worrying about the electronic collection and storage of their PHI (Flynn et al 2003), as well as how their health data will be used (Angst, 2006). The Harris poll (2000) of attitudes to privacy online found that 56% of people would opt out of having their personal information collected if they could (Business Week/Harris Poll, 2000). Therefore, reading the terms and conditions and privacy policy of HSNs should ideally provide information about the disclosure of their PHI with different individuals and organisations, what data is restricted and the exceptions to these restrictions and when their private data will be shared.

Sharing PHI has benefits to improve overall health outcomes by harnessing the power of 'the crowd' (Sarasohn-Kahn, 2008). Some challenges which need to be addressed include improving the current fractured network used to share PHI (Vest and Gamm 2010). Firstly, many stakeholders are responsible for the creation of PHI and very few of them are interconnected (Sharfstein 2015), resulting in people having multiple online health records but no consolidated health record. Secondly, the issue of education around informed consent needs to be addressed (Cockcroft 2010). In the current healthcare landscape many people who create PHI and share it online have little comprehension around how this information will be used (Li 2013). More worryingly, it has been reported that in some circumstances PHI which has

been de-identified and protected, was re-identified via technology (Warren 2016). This engaging piece of research aims to improve both the form and accessibility of contractual information presented to HSN users, and in doing so reveal the challenges and risks of sharing PHI on HSNs resulting in the creation of guidelines which will improve the user's decision making process when using HSNs.

Literature Review

Electronic consent (eConsent) is about "the patient user consenting to their personal health information being accessed and shared" (O'Keefe et al 2005). It is imperative to distinguish between 'patient consent' and 'informed consent' as both terms are often utilised within a healthcare context. According to Cockcroft (2010) 'patient consent' means that a person receiving health care is willing to share PHI and where appropriate to receive a course of medical treatment. 'Informed consent' is much more detailed in the fact that consent reflects that the patient is informed, before any request for information, or treatment (Cockcroft 2010), of the following: Accessibility of the patient record and how it will be shared, used for and by whom. Additionally, it reflects that the patients are aware of the risks associated with their involvement in terms of medical treatment or clinical trials (Galpottage and Norris 2005). Improving patients' awareness around their decision to provide consent (either via paper or digitally) requires a heightened understanding of the terms and conditions and privacy policy statements associated with the trial or in this case HSNs.

There are examples (subsequently described) in healthcare industry worldwide of PHI being used beyond the boundary of the knowledge or comprehension of those who generate the PHI to begin with. An article on the American based modernhealthcare.com website (Peel 2014) entitled 'Research corporations using patient data without consent', outlines one such scenario where PHI was data-mined without patient knowledge by research corporations. This article further argues that roughly 1% of the public would provide consent for their PHI to be used for research purposes (Peel 2014). A more recent similar incident in the United Kingdom was highlighted in November 2016 in an article entitled 'Google secures five-year access to health data of 1.6m people' (Booth 2016). This article discussed the five-year deal between DeepMind (an Artificial intelligence firm) and the Royal Free London National Health System Foundation Trust, to develop a clinical app called Streams. The app is based on PHI access. The article suggests that as a result of this five-year deal DeepMind will be provided with access to health data created by 1.6 million people, over the last five years. Based on this article and other publications in the press, it subsequently was revealed medical records with PHI would be collected on a massive scale and in some cases this would be without the explicit consent or knowledge of patients responsible for generating this medical data.

The Australian healthcare industry saw a comparable instance (cf. Warren 2016). In 2016 the Department of Health published online a dataset which made reference to approximately 3 million people in Australia and included both 'Pharmaceutical Benefits Scheme' claim information and 'Medicare' information. The dataset was described as being de-identified for individual privacy purposes but when tested by a team in the University of Melbourne it became clear that it would be possible to identify people mentioned in this dataset. Morrison, McMillan and Chalmers (2014) found that in general only 20% of people read the terms and conditions; and within their study only 2% opened the terms and conditions page, with 1 person only spending 60 seconds reading the 842 word-long document. The basis for this research examining eConsent is founded on the work of others such as Spiel and Klein (2014), with their research on the effectiveness of electronic personal health records e.g. Microsoft HealthVault. They found that users expressed concern over system safety and the privacy of their PHI (Spiel and Klein, 2014).

The issue may not be the content of these documents per se, but in the way the content is presented (i.e. form and accessibility of contractual information presented to users). Many of these policy documents have been criticised for their length and the complex language used (Flynn 2012; McKee 2013). There have been a number of interventions, albeit limited, to try and address these issues by introducing various approaches into electronic consent procedures. Nishimura (2013) conducted a systematic review of 54 interventions tested in randomized control trials and found various interventions used to help assist with informed consent in a healthcare context. Table 1 presents a snippet of some interventions reported in literature to improve the consent process.

Research	Intervention Used in Healthcare Context	Improving the Consent Process	Healthcare Practitioner present to assist with queries
Henry (2009)	Multimedia tools and technologies (DVD-aided)	High-risk and high-complexity hypothetical clinical trial of an experimental cognitive enhancer medication	Yes
Falagas (2009)	Enhanced design methodologies	Systematic Review	N/A
Barbour and Blumenkrant (1978)	Altered counseling or dialogue/ videotape information package in addition to a standard written consent form	Dialysis/Hospital	Yes
Sarkar (2010)	Provision of quizzes that give immediate feedback	Trial of nutritional supplementation/Hospital	Yes
Simon (2015)	Mulitmedia tools (PowerPoint-type slides)	Biobank/Hospital	Yes

Table 1: Overview of Interventions Used

While some research has looked at the use of multimedia for eConsent, the existing efforts have been confirmed for use within hospital settings with a healthcare practitioner been present to assist with any queries posed by the individual who is providing consent (see Table 1). With HSNs, there is no one available to offer assistance if a question is posed by the user. Furthermore, HSNs are predominantly accessed via mobile technologies (Wright 2016). While having ubiquitous access to HSNs on demand can be beneficial, mobile technologies also have their drawbacks. The main drawback is that the current visualization of the consent process on mobile devices is very restrictive due to screen size and the amount of text visually presented to the user. With the rise of HSNs, patient-generated health data online is increasing. McKee (2013) proposes that a gap exists between user understanding and data usage by HSNs. Simon (2015) argues that research has yet to demonstrate that eConsent processes communicate study information more effectively than traditional F2F methods. However, the authors highlight the work of Mahnke et al. (2014) who argue that the inconsistency in multimedia study results may be due to a lack of rigorous development of multimedia and alternative materials. Therefore, this research aims to improve the form and accessibility of contractual information presented to users of Health Social Networks (HSNs), by looking at alternative ways to communicate these details to users on registration.

Proposed Methodology

This ongoing funded research is in the initial phases of a 12-month project. Ethical approval for this research was granted by University College Cork, Ireland. Taking a mixed methods approach, this research consists of three steps. Step 1 requires participants to register on a HSN using a mock profile, participants will be observed at this stage. Direct observation can provide rich qualitative accounts of device usage and human behavior (Salovaara et al., 2006). While we are aware that participant behaviours may change due to observational reasons (Salovaara et al., 2006), it is important that observation is done to ensure the questionnaire in Step 2 is accurate. In Step 2 participants will be asked to complete a questionnaire based on step 1. During Steps 1 and 2 the participant works independently from other participants. Following this, Step 3 collectively involves participants in a focus group to provide a rich understanding of the eConsent process, allowing the researchers to answer 'How' and 'Why' questions in relation to the study (see Figure 1).

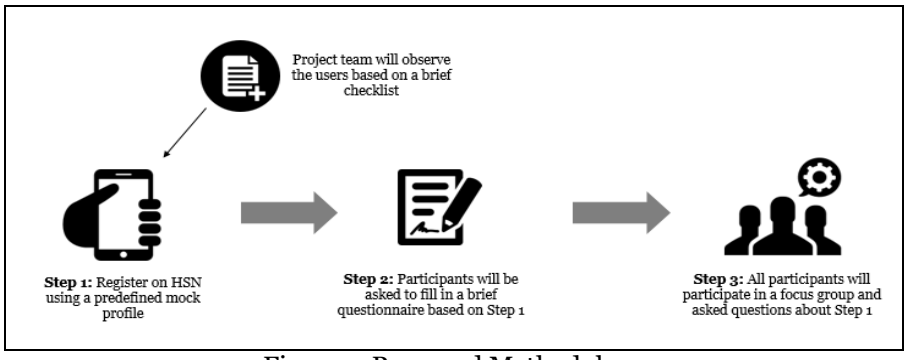

Figure 1: Proposed Methodology

According to Hughes and Gibson (1991, p153) "administering and controlling a field experiment in the area of information systems is a continuing problem". One solution is to utilise a laboratory setting with graduate business students as a surrogate for 'real world' users (Briggs et al., 1996; Hughes and Gibson 1991). A convenience sample of approximately 50 graduate business students will be enlisted to this study. By illuminating the associated challenges and risks, this methodology will provide the tools to improve the presentation of consent information for HSNs by creating a set of guidelines for users.

Discussion and Conclusion

This research will propose a list of design guidelines to better support user's decision making needs when choosing to register and provide PHI to HSNs. The expected contributions for this study is that awareness of the consent process for HSN users is promoted. Further, guidelines for developers of HSNs will be identified to ensure that the informed consent process is transparent to the user while improving the efficiency and effectiveness of digital informed consent giving. This study has the potential to offer improvements both to the users of HSNs and the providers of these services. As Henry Ford (1930) stated "What we call evil, it seems to me, is simply ignorance bumping its head in the dark."

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