

# Poster: Privacy Aspects of Health Related Information Sharing in Online Social Networks

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**Abstract**—Online social networks (OSNs) have formed virtual social networks where people meet and share information. Among all shared information, health related information (HRI) has received considerable attention from researchers and individual users. Although considered beneficial, sharing HRI, which is personal in nature, comes with its privacy drawback. Privacy is a process of boundary regulation that is related to the individual and her perception of the surrounding environment [1]. As a result, the subjective privacy risk perceptions associated with sharing HRI in OSN have driven people to adopt different behaviours, both in terms of HRI sharing and risks mitigation.

In this study, we conducted an online survey to explore users' behaviours in terms of sharing HRI on OSNs. We examined factors that affected users' perceived privacy risks along with their risk-mitigating behaviours. We found that the majority of users shared some HRI through their OSN account(s) (95.8% of 166 participants), while considering the shared HRI "type" and its "recipient" to be more important in forming their perceived privacy risk and possible behavioural responses.

**Index Terms**—HRI, OSN, Risk Perceptions, Behavioural Responses, Mechanical Turk.

## I. INTRODUCTION

Sharing health related information (HRI), such as symptoms, treatments, prescriptions, and diet related information, could be beneficial for individuals and people in their social networks. For example, social pressure has been shown to be an effective incentive for losing weight and can influence people to make healthier lifestyle choices. In addition, patients with serious illnesses can learn from other individuals with similar conditions by connecting through the Internet [2], [3]. Social support is also shown to be effective in maintaining physical and mental health during certain disease treatments [4]. In fact, the highly inter-connected nature of existing online social networks (OSNs), and their increasing number of users have encouraged people to actively use OSNs for sharing different types of information including HRI. According to Pew Internet report in 2013, about 26% of online users have followed their friends' personal health experience in the past year (with a 3% increase when compared to their 2012 report [5]), while 16% of them reported going online to find others who share similar health concerns [6]. Other survey statistics have also shown that sharing health related knowledge is in fact becoming a leading habit among people [5], [6], [2], [3].

Despite of the popularity and the large number of OSN users, existing OSNs suffer from several security and privacy

related issues, making them vulnerable to different attacks [7], [8], [9], [10], [11]. Inherently, OSN users' HRI, which is thought to be personal and private by nature, might be subject to unintended disclosure, resulting inconveniences if shared with unwanted people, and therefore, leading to privacy invasions. According to Altman's "privacy regulation theory", privacy is defined as a dynamic boundary regulation process, where people continuously assess their behaviours and responses in order to minimize the difference between their *achieved* (perceived) and *desired* privacy levels [1]. In reality, depending on their knowledge and previous experience, people perceive privacy risks associated with sharing their HRI on OSNs differently [12], [2], [3], [13], [14], [15]. Therefore, their behavioural responses toward mitigating perceived privacy risks would be variable as well [16]. People may avoid risks by manipulating their information, or cope with the perceived risks for the sake of getting benefits, or simply don't share their information if perceived risks were high [16]. As an example of user behaviours, a study by Velden and El-Emam showed that younger patients, who used Facebook to share different personal information, were not willing to share their HRI on Facebook and preferred to act as "regular" (i.e., with no disease) when communicating with friends on Facebook [15]. On the other hand, a study of US moms, who used online technologies to share or look for HRI, showed that about 70% of them share HRI through their Facebook accounts [17].

Motivated by the need for continuous assessment of users' subjective behaviours, we constructed an online survey to investigate existing practices of sharing HRI in OSNs, explore users' privacy perceptions and risk mitigating behavioural responses. We recruited 166 active OSN users through Crowd-Flower,<sup>1</sup> and surveyed their behaviours in terms of sharing different HRI categories. We obtained different HRI types from literature and categorized them into 8 groups with respect to their characteristics, as shown in Table I. We observed that the majority of participants (95.8% of 166), indicated sharing some HRI through their OSN accounts. Participants shared HRI and experience on OSNs for several reasons, among which "helping others" and "seeking help and social support" received higher responses, with 66.9% and 51.8% respectively. On the other hand, about half of the participants (49.4% of 166) preferred not to share their HRI because they had different people in their OSN contact list and did not

<sup>1</sup>www.crowdflower.com

want to share HRI with all of them. We observed that many users (about 93%) consider the HRI *type* and its *recipient* to contribute the most in increasing the perceived privacy risks. Therefore, participants perceived lower privacy risks when sharing HRI with “select individuals or select groups”, while their risk perceptions increased with the expansion of the receiver base to include “all contacts” and “all OSN users” respectively.

TABLE I  
HRI CATEGORIES.

Category	HRI Examples
Healthy living	dietary and healthy eating, physical exercise, mental exercise, emotional exercise, environmental hazards
Own experience	experience with: previous surgeries, treatments and their side effects, symptoms, specific doctor or medical institute, health insurance companies and plans
Useful found information	books, articles, websites
Mental and emotional health conditions	sad, stressed, happy, excited, depressed, mental disorder
Physical health condition	sick, injured, not feeling good, in good shape, tired
Medical health records	personal information and address, physician and medical institute information, insurance related information, x-rays, reports, appointments and schedule
Experience of somebody else	experience with: previous surgeries, treatments and their side effects, symptoms, specific doctor or medical institute, health insurance companies and plans
HRI of people in your custody	parents, children, and others

In summary, we make the following three contributions in this paper:

- Surveyed a sample of active OSN users for their HRI sharing behaviours and practices.
- Collected quantitative data about OSN users’ HRI sharing practices, perceived privacy risks and risk mitigating behaviours.
- Performed descriptive statistical analysis, summarized main findings, and identified future research directions.

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