Towards a New Trust Model for Health Social Networks

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Abstract—More specific purpose driven social networking sites have emerged since social networking sites have gained popularity by bringing people with shared interests together to interact. In health care, they are referred as Health Social Networks (HSNs). Given the sensitive nature of health information, trust is fundamental for them. The emergence of pervasive and ubiquitous computing environment and overwhelming information available online is helping the health social networking sites gain popularity at a fast pace. Health social networkers are willing to create, share or retrieve trustworthy health or lifestyle related information. Therefore, it is essential that trust is stipulated and scrutinised to understand how the users perceive healthcare, how they decide to interact with HSNs. This paper analyses external factors such as perceived information quality, perceived system quality, perceived reputation and perceived trust signs which impact the trust model for HSNs. In particular, ‘perceived reputation’ based on the factor ‘who has recommended the site’ is given an emphasis on this paper. It highlights that popularity of social networking sites is changing the way trust models have been defined in the past. This is because social relationships created via social networking sites are also impacting on choosing the HSNs and how users are sharing health information on these platforms.

Keywords—Online health information; social networking sites; health social networks; trust model.

I. INTRODUCTION

The use of SNSs (social networking sites) has made a substantial impact on the revolution of health care digital communication. Health information is generally sourced from health care professionals but an increasing number of health care consumers turn to websites and SNSs nowadays for the source or second opinion. Due to both pervasive and ubiquitous nature of ICTs (information and communication technologies), the number of people sharing health information online and the number of social networking sites for health-related information is increasing [1,2,3]. One of the popular topics for people to participate and share online is health-related information. Health information is shared with other users although personal health information is considered to be sensitive. It is one of the basic characteristic of human being that when we experience something positive, we tend to share with peers and recommend others. For example, if we watch a good movie, we tend to recommend this movie to our friends to watch. In a social networking environment, when a user shares information on a particular topic, they discuss their positive experience and subliminally recommend, validate and endorse the experience. In this paper, we use the term ‘HIs’ (health infomediaries) for providers who provide unbiased health information online to users, through which they have choice to make their health related decisions [4]. Another term ‘HSNs’ (health social networks) is used to cover social networking sites where users search, self-track, discuss health and lifestyle or fitness related information [2, 5].

While there is an increasing trend in using the ICTs to search and communicate health information online, the demand for high quality information has also been rising [6]. At the same time, there is also a legitimate concern for security and privacy. The impact of social networks on healthcare is the subject of studies [5] and there are serious concerns as the healthcare consumers rely on the information provided by the health related platforms such as HIs, HSNs, Apps. Despite the warnings ‘not to use the information without consulting a health care professional’, consumers use the information to make health related decisions. Therefore, questions such as, ‘how do health consumers know the platform is trustable and the provided information is well researched? Are the health social network sites safe?’ have risen. Such platforms may have been created to provide information to facilitate sales of a product or service [7] or capture private information in exchange of perceived benefit [3]. Trust plays an important role for healthcare consumers to reduce uncertainty in technology-mediated environment [8].

There have been many studies regarding trust on the websites but only a few researchers have focused on the health related online information. Among them, Song and Zahedi [4] suggested that the quality of information and the level of trust the healthcare consumers have with the health platforms are very important to make their health decisions. It has been argued that the trust would be more reliant on the content for health related information, than other factors such as how it is presented, HCI (Human Computer Interaction) factors or the credibility of the platform. Less priority seems to be given to the factor such as ‘who has recommended the site for the particular health information or to exchange health related information’. Pew Research Center [9] has reported that 80% of Internet users in US have looked for information about health topics or similar health issues they are facing. It has also been reported that over 3,000 hospitals have social networking sites which includes over 700 Facebook pages [10]. However, due to the sensitive nature of the health related information, the health social network
users may disclose information and describe terms which could be misleading or misinterpreted. This certainly creates some challenges to the health social networkers.

This paper is a step towards a new trust model for HSNs. Section 2 defines HSNs and the risks associated with them. Section 3 focuses on trust and discusses its vital role in reducing those risks. Section 4 analyses external factors affecting a concept of trust. Section 5 proposes a new trust model for health care recommendation systems. The paper concludes with open issues and future work.

II. HEALTH SOCIAL NETWORKS AND RISKS

Since SNSSs have been gaining popularity, more specific purpose driven social networks have emerged in addition to the popular sites such as Facebook for general purposes and LinkedIn for career specific. Healthcare consumers (both professionals and consumers) have moved from searching information online to sharing information and in fact interacting with other users within the platforms [11]. They are able to find other users in similar illnesses or health situations and interact with each other about their conditions, symptoms and treatments in the sites like PatientsLikeMe, DailyStrength and many others [1]. This environment provides great opportunities for healthcare consumers to be able to connect and relate with each other [11]. It has been reported that 23% of chronic health e-patients with cancer, diabetes, or heart disease have searched for other patients with similar conditions [11]. Other studies such as ‘Point of Care’ Survey conducted by Wolters Kluwer Health revealed that the physicians have changed initial diagnosis of patients based on new information accessed online resources [12].

With the increased number of healthcare consumers turning to HSNs for retrieving and sharing health information, the number of the users who rely on the information from these platforms is rising. It raises the potential danger of using the health information incorrectly by healthcare consumers in a short or long term. The degree of danger unequivocally depends on the skills and knowledge of the healthcare consumers, such as understanding of medical or scientific vocabulary and biomedical knowledge, to interact with the HSN communities and other health related platforms [2]. BetterHealthChannel [13] has listed some of the potential risks associated with health information online. These include, wrong diagnosis, misunderstanding of medical jargons, self-medication may delay visit to the health professional and hence miss out on appropriate early and appropriate treatment for the illness, a delay may cause serious complications or death, and may have unwanted side effects or interact with other medications.

III. ‘TRUST’ AS A MAJOR FACTOR

Trust is a very complex phenomenon. There are many definitions and studies of trust in many aspects of lives. Many experiments and surveys have been conducted and developed trust models accordingly. Yet there is no universal definition of trust that everybody can share and the concept of trust remains elusive [14]. A simple reason for that is that ‘trust’ has numerous and diverse meanings. On a daily context, ‘trust’ is a term with many meanings [15]. “Trust is an important lubricant of a social system”, because it can enhance efficiency [16]. It has been shown how trust as a high level of altruism can increase efficiency of people working together [17]. In general terms, trust is a relationship between the trustor and the trustee. In the context of health information; the trustor is a health social networker (healthcare consumer) and the trustee is the HSN platform.

Many researchers and scientists have defined and categorised many different types of trust. Among them, Josang et al. [18] used Reliability trust and Decision trust in the context of health information. The measurement of reliability trust is to provide the best health-related information based on ability, knowledge, skills and competence of the trustee (platform or information provider). This could be determined by the credibility, qualification and history of successful stories or case studies provided. Decision trust can be measured based on the actual actions the users take after getting exposed to the information in the platform. This could be influenced by the circumstances the users are in, for example the urgency of the need, or most importantly who has recommended this platform.

Many researchers emphasised the importance of initial trust for users that attract them to visit a platform for the first time. Song and Zahedi [4] designed a trust model and not only focused on the initial trust component for health related platforms, but the dynamics of trust revision as per time of loyal users. Time is important component on measuring trust because the level of trust may increase or decrease over time.

Adams [19] focused on reliability issues in the context of interaction of health consumers with information in the technology-mediated environment. More specifically on the quality of information (credibility and accuracy) and the healthcare consumer’s behavior in terms of creating, exchanging and retrieving within social network environment. Quality of information is not just about ratings of the health information available online [20], but the credibility of the content in line with the concept of reputation and a collective measure of trustworthiness [19]. Reputation building is prevalent within SNSSs and recommendation sites as these platforms provide the opportunities to reach more consumers and facilitate to create, share and retrieve information online. In hindsight, the reputation building process can be manipulated through pre-formatted templates, which could lead to suggest specific products or services [19].

With the increased number of healthcare consumers interacting on HSN platforms, more issues about reliability and trustworthiness will be encountered in making decisions for their health issues. In this paper, an existing trust model for health infomediaries by Song and Zahedi [4] is reviewed. In addition to existing external factors, this model will be altered to emphasize impacts of social influence such as ‘who has referred to this particular HSN platform?’ Later on, a new trust model is proposed.
IV. NEW TRUST MODEL FOR HSNs

The model is based on the framework of TRA (Theory of Reasoned Action) and conceptual trust model designed by Song and Zahedi [4]. TRA has five main components: ‘external factors’, ‘trust beliefs’, ‘trust attitudes’, ‘intentions’, and ‘behavioural outcome’ [21]. These five components lead to develop relationship between the trustor (health social networker) and trustee (HSN platform) and the relationship could be either positive or negative. The five components and the ‘relationship development’ steps are shown in the Fig. 1.

While making decisions, external factors assist to outline the trust beliefs formation. This is what influences the formation of trust attitudes and then intentions towards determining eventual behaviour such as whether to act or not on the information provided or extracted from the HSN platforms for their health issues. TRA considers that trust beliefs lead to trust attitudes, and then they lead to behavioural intentions and becomes behaviour [22].

The first three components from the TRA framework: ‘external factors’, ‘trust beliefs’ and ‘trust attitudes’ are further refined into a conceptual framework and shown in Fig. 2.

The intentions to use health information or take part in interaction or exchange of personal health information in HSN platforms are derived through the level of trust to the particular platform. If the intentions are positive and the experience turns out to be a favourable one, this could lead to the development of a relationship with the HSN platform (trustee). Inherently, health consumer would likely re-visit the platform and recommend the platform to others. This is where power of SNSs comes into play. In terms of gaining the trust, the first impression or initial trust is very important. Through a good initial trust, the users will be willing to use and share health information within the HSN platform. Therefore, social influence ‘who refer to the site’ has a critical role. Once the trust is established, there will be more interactions between the trustor and the trustee over time. The level of trust is determined by the information quality (credibility), system quality and satisfaction to the trustor which will be developed over the time [23].

A. Perceived Information Quality

The measurement of information quality is evolving with the pervasive ICTs in the healthcare domain. In the model we selected, perceived information quality has been further classified into the following sub-categories:

- **Understandability**: Understandability means clarity of the information to the user. Medical and scientific vocabulary could create challenges or users to understand. As long as the HSN platform is destined for the general public, the trustor needs to be careful of the vocabulary used. There is always a danger that users may misunderstand the terminologies used.
- **Relevance**: Relevance refers to the appropriateness of the information to the users. If the information is understood, the users are able to verify whether it is relevant to their needs. Medical or health related knowledge is important to understand the relevance.
- **Usefulness**: Due to the sensitive nature of health information, healthcare consumers are concerned about
any form of digital communication. Perceived usefulness (PU) of the extracted information influences the trust beliefs to a positive territory and eventually influences behavioural intentions [24].

- **Reliability**: Reliability refers to the credibility of the trustee and the accuracy of the information. It is a broad terminology and may well incorporate technical aspects of the platform and health consumer behavior [19].

- **Adequacy**: Adequacy refers to the completeness and references provided. Completeness means an extensive coverage of health-related information on the specific topic. This could portray as a sign of the commitment of the platform to the users by providing unbiased information and references.

Besides these sub-categories, there are many other important factors to qualify health-related information quality such as timeliness, accuracy, clarity and so on. They are not covered in the model in the Fig 2.

**B. Perceived System Quality**

A study was carried out to determine overall satisfaction with system quality and information quality for health information. It was reported that system quality (usability) played a greater role than information quality in the study [25]. Both perceived ease of use (PEOU) and perceived usefulness (PU) are basic ingredients to support the technology acceptance model (TAM), an information system theory which models how users accept and use a technology. This theory later forms the trust antecedents of intentions to utilise the health-related information, as intended at the time of creation [26].

- **Ease of use**: The ease of use refers to the usability of the HSN platform which will determine whether the users want to spend time on it. Perceived ease of use (PEOU) influences the perceived usefulness (PU).

- **Interactivity**: Interactivity refers to the web features that ease the user’s experience for the search and potentially even personalize the information based on the search criteria.

**C. Perceived Reputation**

The term reputation can be defined as the social influence of trust, which can be referred as social exchange theory that define one party’s reputation based on a third party’s ability to tell stories about its trustworthiness. The terms ‘reputation’ and ‘trust’ are strongly linked to each other. Reputation is usually influenced by the past behaviour. A repeated visit and prior positive experience of health consumer with the platform denotes the perceived reputation. Any good or bad experiences or result is easily circulated via social networking sites instantly. It is even more important for health-related information to be distributed faster if more people to get benefit or protect from.

**D. Perceived Trust Signs**

Trust signs are used to reassure the healthcare consumers that there are no risks associated with HSN platforms to interact to or retrieve information from and reinforce integrity of the provider. The use of trust signs is necessary to convince the users that they can trust the HSN platform and its information [4].

Deshpande and Jadad [20] provided five broad categories to evaluate the quality of online health information and depicted as trust signs:

- Codes of conduct (e.g., Australian Medical Association),
- Quality labels (e.g., Health on the Net Foundation [HONcode]),
- User guides (e.g., DISCERN Online),
- Filters (e.g., intute.ac.uk) and
- Third party certification (e.g., Hi-ethics, Utilization Review Accreditation Commission [URAC])

Overall, the external factors from the conceptual model in Figure 2 influence the trust beliefs and ultimately influence the HSN platform user’s intention to act on the information extracted from HSN platforms. If the perceived information quality, perceived system quality, perceived reputation, perceived trust signs and satisfaction are all positive, the HSN platform users will come back to retrieve and share health information in the HSN platform and in fact recommend to others [27]. Loyalty is critical to sustain the systems however these information tend to have temporal effect as soon as the user receive the required information, there is no incentive for them to come back. The user satisfaction is what makes the users loyal and recommend the system to others.

Intention of using the information extracted from the HSN platform is significantly relied on the urgency of the matter, need and circumstances of the person at the time and the trust is crucial for these circumstances. From the conceptual trust model, the impact of the external factors, specifically the influence from the third party based on who has recommended visiting the HSN platform, will be researched further. This factor is very dynamic and very complicated to measure as these variables would change from case to case.

**V. PROPOSED MODEL**

The conceptual trust model analysed external factors which affects trust in the health information and the health related platforms. However, in this research, we focus on the perceived reputations, one of the external factors and specifically, impact of ‘who recommended the platform or information?’

Since the explosion of social media, more information is being shared online. The social behavior of human being has been replicated in social reviews sites or recommendation sites by allowing more users to interact and share their experiences in an unbiased environment. Depending on who recommended the health platform or information provider, users have tendency to follow through better. If the experience is good and satisfied during the process, they will tend to continue to use and recommend to others further. Based on this, a new trust-based model for dynamic
healthcare recommendation system is proposed as shown in the Fig. 3.

This model has 3 steps. Firstly, users or patients will have some preferences (criteria) while searching for health-related information or healthcare providers. The criteria such as location, symptoms, age, specialist, availability and others are used. Based on these criteria, a system would provide a list of health-related information or providers. Which one in the list to use in this information overloaded age?

Because people tend to rely more on recommendations from people they trust, we would evaluate trust within their own social networks which can help to sort out the list from the previous step. The trust is what would influence how and what information is going to be used by the users. There are many ways to evaluate trust within SNS. The evaluation of trust in our research will be done by analysing the strength of relationships among users in the social network. The influence is directly proportionate to strength of relationships. Analysis of similarity in the context is another element we will focus on, such as symptoms, side-effects, and behaviours among the users. In addition, influence could also be determined by how knowledgeable the trustee in the specific healthcare area is. If the person is an expert in the area, his/her opinion will be given more priority by the trustor. Analysing these information, a trust value would be generated. Based on the trust value, the health information or the healthcare provider would be selected.

In some cases, the users or patients are able to verify the information (or provider) further with the existing online information (crowdsources) to assure that the information is trustworthy. It is the last step of the proposed model, which is an alternative, because the information may not be available for all information (or providers).

This model accommodates the users’ preferences (criteria) and users’ trust within their own network to be able to filter through to the best possible result while looking for health-related information or healthcare providers.

VI. OPEN ISSUES AND FUTURE WORK

SNSs are open platform for communication and they provide a meeting place to create and share experiences in life. Users share information with each other in the SNSs, regardless of whether knowing or not knowing the remote user, which provides both opportunities and challenges for sensitive health information. How do we know the information publicised on the HSNs or shared in the SNSs are accurate? Not only content but also the source of the information is very important. The search engines cannot provide whether the source is trustworthy or not. Trust has been regarded as one of the major factors the users consider in the process of searching and taking actions on health-related information. Yet, it is very subjective to determine the trust value as it is extremely dynamic and changes quickly with many dependent variables such as time, situation, knowledge, experiences and many others.

In the future work, we will focus on the impacts of health social networks to the trust model and test some hypotheses to prove the significance of the impacts on the model in specific health care areas such as dental care. We will divide trust into internal (local) and external (global) trust factors. Internal trust is generated within a user either through existing relationships in their network or through their sharing experience in a particular HSN. External trust will be through existing ratings and review sites about the health information online. Impacts of reviews and recommendations in conjunction with own level of trust to the health platform and a particular information provider as a trustee will be studied further in the domain.

REFERENCES


Figure 3. Proposed Model


