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Exploring the Situational Approach to Decision Making: User eConsent on a Health Social Network

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***Abstract*—**Situation Awareness can offer the potential for conscious dynamic reflection. In an era of online health data sharing, it is becoming increasingly important that users of health social networks (HSNs) have the information necessary to make informed decisions as part of the registration process and in the provision of eConsent. This research aims to leverage an adapted Situation Awareness (SA) model to explore users' decision making processes in the provision of eConsent. A HSN platform was used to investigate these behaviours. A mixed methods approach was taken. This involved the observation of registration behaviours followed by a questionnaire and focus group/s. Early results suggest that users are apt to automatically accept eConsent, and only later consider the long-term implications of sharing their personal health information. Further steps are required to continue developing knowledge and understanding of this important eConsent process. The next step in this research will be to develop a set of guidelines for the improved presentation of eConsent on the HSN platform.

***Keywords*—**eConsent, health social network, mixed methods, situation awareness.

I. Introduction

MAKING a good decision can be difficult, often involving effort, time and much cognitive capacity. The normal process of weighing up the available information maybe the most accurate but, this also comes with costs in time and effort [1]. A positive precursor to good decision making has been identified by Endsley [2] in the form of SA. By using SA, social and cognitive skills can be used to influence and improve decision making. Decision making impacts on every aspect of a person's lifestyle, and increasingly in the use of technology; it is said that social media is a driving factor in influencing consumer behaviours [3]. However, technology is not just about consumerism, it is also about social networking - sharing our personal details with others. This has led to a rise in the development of HSNs whereby "people connect with each other around common problems and share relevant health data" [4, p. 704]. But how are people deciding to join these HSNs, and on what basis are they making these decisions – are they situation aware of the choices they are making? This research aims to look at user behaviour when providing eConsent on a HSN taking a mixed methods approach to the collection of data. By exploring user behaviours in this way, our aim is to understand this particular decision making process by taking a SA approach to the analysis of the findings.

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II. Background

A. Situation Awareness (SA)

The origins of SA have arisen from the aviation industry where it was used to understand causes of decision error and for safe decision making [5]. SA can be understood as "the perception of the elements in the environment in a volume of time and space, the comprehension of their meaning, and the projection of their status in the near future" [2, p. 36]. The psychological stance taken in this version of SA is based on cognitive theory – an information processing approach [6]. The cognitive processes underlying SA involve the integration of knowledge derived from recurring situational assessments, which are assessed via perception and pattern matching [2]. Thus, an individual's awareness is comprised of their conscious and available mental constructs [6]. Endsley's three level model describes SA as an internal product that comprises hierarchical levels which are separate to the processes used to achieve it. This model has an information processing component that follows perception, leading to decision making and action. The acquisition and maintenance of SA is influenced by the individual, the task and systemic factors [2].

The first step in level 1 of this SA model involves the perception of the elements i.e. the status, attributes and dynamics of the task-related elements in the environment. Level 2 focuses on the interpretation of level 1 data, so that the individual can understand or comprehend its relevance in relation to the task and goals. This creates a holistic picture of the environment – the significance of objects and events. Level 3 uses the information garnered from level 1 and level 2 to facilitate the projection of future states of the system and elements in the environment. Knowledge and experience, in the form of mental models, from the combination of level 1 and level 2 allows individuals to forecast future states in the situation. Fig. 1 illustrates an adapted simplified version of Endsley's SA model.

A key assumption in the three tier model is the critical role of mental models. Endsley suggests that features in the environment are mapped to mental models in a person's mind and that these facilitate the development of SA [2]. The SA model offers simplicity; the three levels allow the SA construct to be easily and effectively assessed.

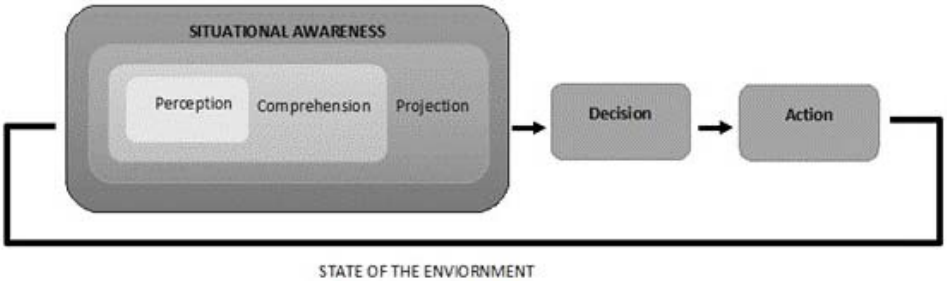


Fig. 1 Three level model of SA (adapted from [2])

B. Research Framework

The SA framework is used to identify the informed consent elements that are important to users which result in decisional autonomy, when making the decision to give consent to a HSN's privacy policy. The provision of informed consent results in the sharing of personal health information (PHI). Awareness is the prerequisite of comprehension that requires the users to be at the very least aware that they are consenting to a privacy policy and have read the policy. Both privacy concern and technical protection explore the phenomena of the 'privacy paradox'. This is done by assessing the degree to which users are worried about the possible online security and privacy risks and whether they take steps to safeguard against these risks. Satisfaction with policy is the user's satisfaction with the key terms of the privacy policy and associated terms and conditions. Decisional autonomy refers to the outcome i.e. were users satisfied that they made the voluntary decision to consent/refuse the HSN privacy policy and terms and conditions.

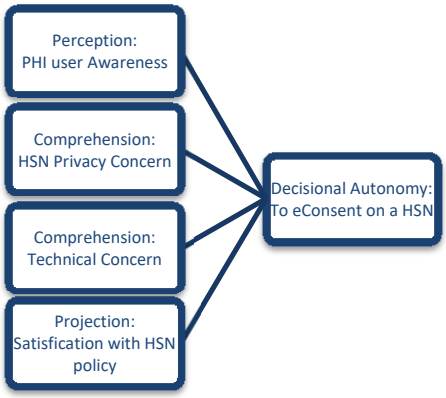


Fig. 2 The integrated SA model [2] with eConsent on a HSN

The framework used to analyze the results from this research can be seen in Fig. 2. This is an adaptation of the SA model is used as the basis for understanding users' decision making process when providing eConsent to a HSN.

Adopting SA to the area of informed consent for HSNs is appropriate, as HSNs play a critical role in the modern healthcare ecosystem. Patients, in particular, can access these virtual communities where they can share detailed health data, such as symptoms and treatments, in order to learn from others, improve their health outcomes and contribute to society [7]. HSNs are often designed in a way which may result in patients unintentionally providing consent without fully understanding how and why their data will be utilised for research purposes and the subsequent advantages, disadvantages and achievable outcomes associated with the use of this data [8]. The concept of awareness (i.e. Perception) is the prerequisite of comprehension that requires the users to be at the very least aware that they are consenting to a policy and have read the policy [2]. To examine comprehension both the concepts of 'privacy concern' and 'technical protection' can be employed to explore the phenomena of the 'privacy paradox', by assessing the degree to which users are worried about the possible online security and privacy risks and whether they take steps to safeguard against these risks [9]. Satisfaction with policy is the user's satisfaction with the key terms of the privacy policy and terms and conditions. Decisional autonomy is the outcome, the understanding that users are satisfied that they made the voluntary decision to consent/refuse the HSN privacy policy and terms and conditions. Therefore, SA can assist with investigating the informed consent elements that influence decisional autonomy when choosing to consent (or not) to a HSN's privacy policy and terms and conditions [10].

C. Perception Awareness

There is anecdotal evidence to suggest that users of HSNs are not aware of the business model these services adhere to – such as selling aggregate data and the possibility of re-identification of personal data. There was a case of the media research firm - Nielson Company – scraping private messages from several forums on HSNs and selling the raw data to various companies, including pharmaceutical companies [11]. What distressed users the most was that HSNs were also selling user data to third party companies and user's claimed they were not aware of this type of activity going on with their PHI. Therefore, it is important to explore users' awareness of the privacy policy and terms and conditions of the HSN site when users provide eConsent to this service.

D. Comprehension: Privacy Concern

PHI is sensitive and high-risk information to individuals and if disclosed could potentially cause stigma, discrimination and harm [12]. There is a real risk that PHI on HSN's like HSNs can be aggregated to re-identify users and thus concerns about data privacy are understandable [13], [14]. However, others suggest that user's expectation of privacy is unrealistic

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given the online environment [15]. Given the lack of control and high-risk nature of sharing PHI online, it is somewhat surprising that people are willing to share such information [16]. One explanation may be the "control paradox", whereby users have a false confidence that they are in control of their personal information [17]. While users may benefit from this idea, this is in fact illusionary. So, such a discrepancy between expectation and reality may in some way account for people's willingness to share their PHI online. By looking more closely at this aspect of consenting to a HSN it is hoped to shed light on these tensions.

E. Comprehension: Technical Concern

Hochhauser lists several usability issues associated with e-consent (consent for research studies) that are equally applicable to online informed consent, particularly where mobile devices are being used [18]. These include (1) reading from a device being more time consuming; (2) presenting too much information on multiple small screens; (3) not all users being technologically savvy; (4) reading from devices not allowing for deeper processing of information; and, (5) text not being legible on a device. The contention being that these issues converge to produce Kahneman's "law of least effort", if there are several ways to reach a goal people will choose the one that requires the least effort [19]. If people are struggling to navigate the device and/or too much information it is likely they will skip the process and consent without any understanding of the terms. Whether this is an issue for users providing eConsent to a HSN or not, will be of interest to this piece of research.

F. Projection: Satisfaction with Policy

The sensitivity and value of PHI along with the risk of sharing such information creates a risky environment for users, many of whom maybe unaware of the full extent of these risks. Pool suggests one approach could include the creation of new regulation to address the unique challenges of sharing PHI on a social networking environment [20]. Whereas others propose a more holistic approach to the formulation of new privacy regulations, which would include a discussion on the awareness, education, design and regulation of these services, to address privacy threats from the HSN platform, the users own behaviours and the lack of legislation [4]. A holistic approach could address the three aspects of privacy – 1) privacy by design, 2) education, and 3) awareness [20]. If such an approach was offered to address privacy concerns, then perhaps users would be more satisfied when asked to provide eConsent to a HSN. It is hoped that by exploring user's behaviours when consenting to a HSN that satisfaction with such policies can be evaluated.

III. Method

This funded research is in the initial phases of a 12-month project. Ethical approval for this research was granted by UCC Social Research Ethics Committee. Taking a mixed methods approach, data collection included a three-step process. Step 1 required participants to register on a HSN using a mock profile, participants were observed at this stage. Direct observation was used as this can provide rich qualitative accounts of device usage and human behaviour [21]. Though the observation of participant behaviour has the potential to change these behaviours, it was important to do this to ensure that this stage was completed [21]. Step 2 included the participants then completing a questionnaire, which was based on an adaptation of Endsley's model of SA. During step 1 and step 2 each participant worked independently. In step 3 all participants were involved in focus group discussions. Three separate focus groups were held and these took place immediately after step 1 and step 2. Participant numbers at these focus groups were 10:8:6, respectively. A focus group approach was employed to provide a richer understanding of the eConsent process and reveal insights into the "How" and "Why" questions of the research. The questionnaire and the focus groups questions focused on four categories of detail: 1) Perception – user awareness of eConsent; 2) Comprehension – HSN privacy concern and technical concerns; 3) Projection – satisfaction with the HSN policy; and 4) Decision Autonomy – users eConsent to the HSN.

A. Sample

A convenient sample of 24 graduate business students were enlisted to this study, aged ranged between 18 and 44 years, the majority of which were aged between 25 to 34 years (62%). The gender mix was Male 3:1 Female ratio. Existing research states that "administering and controlling a field experiment in the area of information systems is a continuing problem" [22, p. 153]. One solution is to use a laboratory setting with graduate business students as a surrogate for 'real world' users [22], [23].

Three focus groups were held, and the coding of responses is in line with the collection of data. Participants' responses have been coded as follows: Focus group one – F1, Focus group two – F2, and Focus group three – F3. Any group responses have been labelled as – General Response. The gender of participants in each group is simply represented by the code M or F followed by a number.

IV. Results

Observation of users at time of HSN registration revealed that very little time, on average less than one minute was spent on eConsent; in finding, reading and understanding the Terms and Conditions and Privacy Policy on the HSN in question.

A. Perception Awareness

In terms of the users' perception of the eConsent process on this HSN, 66% stated they were aware of being asked to provide eConsent and 44% were unaware of this. This was by focus groups discussions where participants expressed their behaviours as automatic "I just ticked away" (F1:M1). This ultimately led to participants not reading or understanding the HSN Terms and Conditions (T&C), and Privacy Policy (PP) – 84% acknowledged that they did not read either of these documents. Interestingly, between 50% – 58% of participants stated they did not understand these documents, with the

remainder unsure that they would understand such documents had they read them. Some of the reasons participants felt these doubts over T&C and PP, was emphasized by comments in focus groups "they are too long, too complicated" (General Response F1) and "they are not written to be read" (F2:M2).

B. Comprehension: Privacy Concern

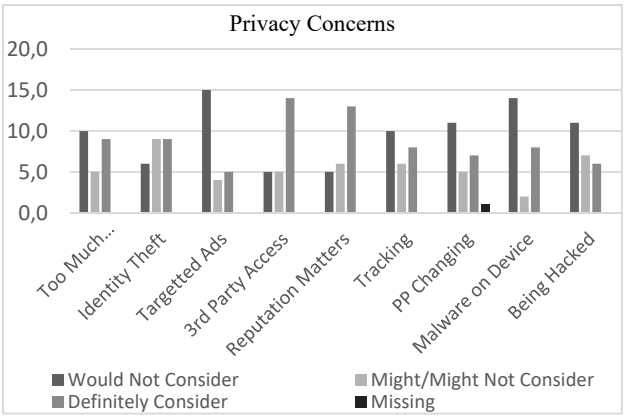


Fig. 3 Representation of HSN user Privacy Concerns

Fig. 3 displays feedback from participants regarding their privacy concerns. We see that 42% of participants would not consider the issue of their HSN account being hacked. Likewise, 62% stated they had not considered the potential for online Identity theft. Other factors that had not been considered by these participants, also included the possibility for social networks trying tracking individuals after leaving this HSN site (46%), the threat of malicious malware being installed on their device (46%), that information from this account could be applied to situations where reputation matters e.g. employers or landlords (42%), and that the HSN could change the PP after a user account is created (58%). However, participants had considered the potential impact of joining this HSN in terms of advertisers using their personal information to better target ads (58%), and third parties gaining access to their personal information (54%). The focus group discussions were mostly in support of these statements, third parties accessing HSN data was viewed as: "I wouldn't be happy with Third Party stuff" (F3:M3) and "I don't think there is any advantage for me personally, it's all for the Third Parties. They are the one's getting all the advantages" (F3:F1). It was apparent that participants recognized the possibility of HSN information being used to target ads "they know who to target" (F2:F1, F3:M5, F3:M2).

In terms of being asked too much personal information there was a fairly even split between considering and not considering this aspect. This was reflected by comments made in the focus groups – "You are giving away a lot of information" (F1:M3) and "I would want much more information on what you were actually signing up to … because you are giving far more information" (F1:F1). As opposed to "I don't think I would have a problem giving away my most personal information when signing up to a HSN" (F1:M1) and "Maybe if you had the option though … if you could decide what information could get shared" (F1:F2).

C. Comprehension: Technical Protection

The understanding the technical protection of their health information on a HSN, 75% of participants had no concern regarding HSN registration via a mobile phone. So, the issue of smaller devices impacting on the usability of a HSN was not a significant factor for participants of this study. Other technical considerations that could have been taken into account are illustrated in the Table I.

TABLE I
THE COMPREHENSION OF TECHNICAL PROTECTION PRACTICES WHEN REGISTERING FOR A HSN

Technical Protection Practices	Would Consider (%)	Would Not Consider (%)
Using a unique & strong password.	21	58
For security questions, providing unique information to me, not known to others.	46	33
Not using a work-associated Email on registration.	87	8
Not using my real name (esp. last name) as a username.	34	57
Looked at PP to see who could view my personal information.	24	70
Did not share my DOB, Age or Place of Birth.	29	53
I deleted Cookies every time I left HSN.	4	95

Some participants had some concerns including the use of a work email as part of the registration information process and providing unique information on themselves for security questions. However, the issues around deleting Cookies, being informed about who could view their personal information and using strong passwords for protection were not taken into consideration when registering for this HSN. Of course, the use of a mock profile could have impacted on these perceptions regarding the technical protections participants should take into consideration. In the focus groups there was comments on this: "If it was my own information, then I would have gone through it with a toothcomb to make sure that I absolutely know what was going on" and "Because of using fake information … you really didn't look at the T&C and PP" (F2:M3). But participants did raise concerns about their private health information being tracked and traced: "Even using other social networks, intelligent tools can extract your health profile in some sense." "If you leave some photo somewhere, there are tools that can extract your health profile" (F2:M5). "What it should be like, … is the restricted data and cookies, be explained, how your data is used" (F3:M3).

D. Projection: Satisfaction with Policy

When it came to the projection of possible privacy issues surrounding eConsent on a HSN, participants were consistent in stating that they estimated their personal health data would be vulnerable to multiple risks. These included selling and scraping of data, potential discrimination by future employers and insurance companies based on the health information supplied, being identified from health details, not having any legal redress to the abuse of data as regulation is currently insufficient in this domain (see Table II). In focus groups these themes recurred: "It could affect you getting Health Insurance

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in the future" (F1:F2). "If they use this information to predict my future behaviour, future health, then that's wrong" (F2:M5). "I don't think I would sign up for it because you don't know what they are going to do with your data" (F1:M2). "No way would I want any Health Insurance, Employer or anyone to find about my health information" (F3:F1). On the view of regulation one comment was: "If there was a real legal backing to the protection of information, an incentive like that, I'd be more comfortable, but I don't think legally there is" (F2:F2).

TABLE II
HSN USERS ANTICIPATED CONSEQUENCES FOR THEIR PHI

Projection and Satisfaction	Concern over these issues (%)
PHI not legally covered by data protection legislation.	58
Possible to find my ID from PHI.	71
Employers, Health Insurance could discriminate against me based on PHI.	91
All personal information I share can be sold to 3rd Parties.	79
My data could be exposed to unauthorised collection.	84
I cannot "opt out" of this HSN selling my PHI.	83

In summary, when it comes to decision autonomy 50% of participants in this study did not feel adequately informed about the issues pertinent to their decision (29% were unsure) and 46% were not happy with their decision (12% were unsure). This resulted in 41% of participants stating they were satisfied that the decision they made was consistent with their personal values, with 25% unsure and 33% dissatisfied. Interestingly, 75% stated that they felt that it was their decision to make. Only 4% of participants were unsure about this statement. There was general consensus that participants were unhappy about the level of PHI being shared, the selling of PHI to third parties, and the overall levels of security and privacy of their PHI on this HSN. So, although participants were able to project future states for the sharing of their PHI on this HSN, they were less clear on their satisfaction with decision making to registering and the provision of eConsent. This is consistent with Endsley's model, if level 1 and level 2 in the perception/comprehension of the task-related elements of the environment are not fully understood, then there will discordance in level 3 and being satisfied with the decision made – in this instance providing eConsent on a HSN [2].

V. DISCUSSION

SA applied to the provision of eConsent through a HSN has been a good starting point in understanding users' decision making processes. From this exploratory research into user behaviours it was clear that these users were aware of the consent process but, did not engage in fact finding – reading the T&C and PP to improve their knowledge and understanding of these statements. In terms of comprehending the privacy risks and technical protection offered by this HSN, without reading the relevant statements on these, user's judgements were disadvantaged by this lack of engagement. There is an obvious connection between this lack of knowledge and understanding of HSN policies and user satisfaction and the key themes highlighted in the data. Decisional autonomy found in this piece of research was mixed, user's recognizing it was their decision to register but, also unhappy with the method used to present the information in the T&C and PP which they were consenting to. This SA model is useful to help interpret the decision situation to make more informed decision. This is supported by the work of Guimond [24] where SA is considered to enhance cognition and the decision making process. The simplicity and division of SA into three levels also supports the development of training strategies and design guidelines to acquire different SA levels [25]. However, when SA lapses occur there is a greater potential for decision making deficits. Similarly, SA can also be lacking when decisions are compromised by other factors e.g. time [26]. There have been questions about the similarities between the three level model of SA and the construct of working memory [25]. With others suggesting the reference to mental models in SA – which are ill-defined – as problematic [27]. The SA model used in this research did offer a simple intuitive description; the three levels assisted with the measurement of the eConsent process on HSN, and considered numerous factors within this eConsent process.

The original aim of this research is to illuminate the user behaviours when providing eConsent on a HSN, to that extent this has been achieved. Next steps for this research involves taking a larger sample set, reviewing the methodological approach, extending the data collection tools and addressing the limitations of this current study e.g. the mock profile user effects. It is acknowledged that findings that emerged from this research are preliminary and that additional research will improve our understanding of the issues uncovered here.

VI. CONCLUSION

Users enjoy many benefits as HSN members. These sites promote sharing health experiences, increasing patient autonomy and offering information for the development of knowledge in wider society [4]. However, there are ethical concerns with HSN use, especially if users are unaware of how their information is used and who it is shared with. These reasons make it more important for HSN users to increase their understanding of the eConsent process and the attached T&C and PP documents. Thus, user's SA when making decisions to join and register are important issues to continue investigating. The next step in the research process is to look at alternative formats for the presentation of T&C and PP to users on a HSN, so that users become educated about the privacy, usability and accessibility of their shared PHI data.

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