Comprehension, Perception, and Projection:
The Role of Situation Awareness in User Decision Autonomy When Providing eConsent

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ABSTRACT

Health social networks (HSNs) allow individuals with health information needs to connect and discuss health-related issues online. Political-technology intertwinement (e.g., GDPR and digital technology) highlights that users need to be aware, understand, and willing to provide electronic consent (e-consent) when sharing personal information online. The objective of this study is to explore the 'As-Is' factors which impact individuals' decisional autonomy when consenting to the privacy policy (PP) and terms and conditions (T&Cs) on a HSN. The authors use a situational awareness (SA) lens to examine decision autonomy when providing e-consent. A mixed-methods approach reveals that technical and privacy comprehension, user perceptions, and projection of future consequences impact participants' decision autonomy in providing e-consent. Without dealing with the privacy paradox at the outset, decision awareness and decision satisfaction is negatively impacted. Movement away from clickwrap online consent to customised two-way engagement is the way forward for the design of e-consent.

KEYWORDS

Big Data, Decision Autonomy, Decision Making, Electronic Consent, Health-Related Social Networks, Situation Awareness

1. INTRODUCTION

Decision making in the use of technology is important, with concerns over users being truly informed about the choices they make online (Williams, Burnap, Sloan, Jessop, & Lepps, 2017). Many social networking sites exist where individuals create public profiles within a service, connecting with other users (Boyd, 2007; Jeong & Kim, 2017; Li, Cheng, & Teng, 2020; Ortiz, Chih, & Tsai, 2018; Rathore, Sharma, Loia, Jeong, & Park, 2017). A growing number of users leverage online fora in an

attempt to finding information relevant to their healthcare needs (Choi et al., 2017). This has led to the development and proliferation of Health Social Networks (HSNs).

HSNs are online services where people connect and share relevant health data (Li, 2013). HSNs offer users emotional support, Q&A with physicians, quantified self-tracking and/or access to clinical trials (Choi et al., 2017; O'Leary, Coulson, Perez-Vallejos, & McAuley, 2020). The key value for users is their ability to connect with others with similar health situations (Choi et al., 2017; Meng, 2016; Swan, 2009). When individuals share personal health information (PHI) online, they contribute to 'big data sets' that could potentially be used for medical research or by other third parties (Lee, Park, Chang, & Ko, 2019; Leon-Sanz, 2019; Murdoch & Detsky, 2013). Some HSNs sell anonymized PHI data to pharmaceutical companies, universities, and research labs (Bouraga, Jureta, & Faulkner, 2019; Kotsilieris, Pavlaki, Christopoulou, & Anagnostopoulos, 2017; Swan, 2009).

Existing research recognises the affordances of 'big data' in the health domain, extolling big data as an opportunity to leverage patient and practitioner data as a means of improving the quality and efficiency of healthcare systems (Horehájová & Marasová, 2020; McAfee, Brynjolfsson, & Davenport, 2012; Milenkovic, Vukmirovic, & Milenkovic, 2019). Big data has the potential to improve problem solving by providing greater insight into complex issues (Madden, Gilman, Levy, & Marwick, 2017). Given the existence of these big data sets the evolution of big data analytics is inevitable, bringing with it several challenges including the need to establish robust privacy and security standards and governance to protect patients and their PHI (Price, 2020; Price & Cohen, 2019; Raghupathi & Raghupathi, 2014; Sharma, Singh, & Rehman, 2020). Madden, Gilman, Levy & Marwick, (2017) remind us that big data holds the risk of information misuse, a "black box society" (Pasquale, 2015), a "transparency paradox" (Richards & King, 2013) and a lack of "algorithmic accountability" (Rosenblat, Kneese, & Boyd, 2014) where the individual is oblivious as to how their data is being manipulated (Madden et al., 2017).

Increasingly healthcare professionals are intrigued by the possibility of uncovering new and exciting findings in population health spanning the broad spectrum of disease pathologies, in an increasingly complex global health data ecosystem (Chen, Lin, & Wu, 2020; Holzinger, Kieseberg, Weippl, & Tjoa, 2018; Power & Heavin, 2017). It is suggested that PHI is a by-product rather than a method for improving healthcare outcomes (Murdoch & Detsky, 2013). Extracting knowledge from big data on health creates considerable research and practical issues. This is especially relevant considering the HIPAA (Health Insurance Portability and Accountability Act) and IRB (Institutional Review Board) guidelines for developing a privacy-preserving, secure health infrastructure, applied to conducting ethical health research (Gelfand, 2012) and GDPR (Starkbaum & Felt, 2019).

There are concerns that individuals are generally unaware of the privacy and security risks associated with sharing their PHI online (Shen et al., 2019a; Shen et al., 2019b). Digital platforms, such as HSNs, could be accused of a lack of transparency and accountability (Solove, 2007; Obar & Oeldorf-Hirsch, 2020). Hui, Tan, & Goh (2006) suggest that individuals, who may initially doubt the use of their personal data by an information system, may overcome this concern in a situation where there is a saving in time and money, self-enhancements, or pleasure. There may be psychological limitations in terms of the user not being able to process all relevant information to make a cost-benefit judgement on the privacy and security of their data, or a user may be overly motivated to obtain immediate gratification by accessing a system or application (Acquisti, 2004, 2009; Acquisti & Grossklags, 2005; Wilson & Valacich, 2012).

Due to the large amounts of information included in agreements such as the Privacy Policy (PP) and Terms & Conditions (T&Cs) in mHealth applications, it is likely that patients will not give enough time to read and fully understand these before providing consent (Schairer, Rubanovich & Bloss, 2018). This may result in users providing "uninformed" consent rather than informed consent (Schairer et al., 2018). Research has shown that when the cost of the reading PP is too high, individuals do not read them (Cranor, Guduru, & Arjula, 2006). Cost in terms of the 'time taken' to read the PP weighted against the potential benefits of engaging with these documents is important

when deciding to expend effort. Inevitably the evaluation of these costs result in individuals choosing not to read the PP's (McDonald & Cranor, 2008). Studies have shown that PPs are difficult to read, are seldom read and do not help in decision making (Aïmeur, Lawani, & Dalkir, 2016); Acquisti & Grossklags, 2005; Jensen & Potts, 2004; Jensen, Potts, & Jensen, 2005). If online services are not effectively communicating PPs to users, in an easy to interpret manner, and to be understood, then perhaps these PPs are misleading the online citizen. This is especially relevant when considering the collection of sensitive health data online (Reidenberg et al., 2015). With the push to move towards a more transparent use of online citizen data through the introduction of more robust data protection legislation across Europe (GDPR, 2018), services need to improve their eConsent designs (O'Connor et al., 2017).

Informed consent can be viewed as both a mandatory and basic right for patients and research participants alike (Getz, 2002). The purpose of informed consent is to ensure that enough correct information is provided to individuals to enable them to judge the costs and benefits associated in consenting to a service or piece of research (McGuire & Beskow, 2010). Informed consent in healthcare settings convey the risks and benefits to individuals undergoing surgery or considering experimental treatment programs. In this context, informed consent works because it is embedded within systems of supporting assurances – there is an interest in the individual's well-being (Nissenbaum, 2011; Utz, Degeling, Fahl, Schaub, & Holz, 2019). Informed consent implies that individuals are knowledgeable about all aspects of the service they are consenting to (Lunt, Connor, Skinner, & Brogden, 2019) . With eConsent on social networks, the provision of PP and T&Cs form implied consent (Obar & Oeldorf-Hirsch, 2016). PP and T&Cs are often presented to the user after clicking a link on the HSN service. Typically, this redirects the user to a new tab or window, ultimately drawing the user away from the main site (Assale, Barbero, & Cabitza, 2019; Lindegren, Karegar, Kane, & Pettersson, 2019; Sadeh et al., 2009). This approach may be less than acceptable to users considering the sensitive nature of PHI on health-related services. In the online environment, eConsent and assurances of online privacy are laden by the regime of the "take it" or "leave it" approach (Assale et al., 2019; Iwaya, Li, Fischer-Hübner, Åhlfeldt, & Martucci, 2019; Lindegren et al., 2019; Nissenbaum, 2011; O'Connor, Rowan, & Heavin, 2018; Wilbanks, 2018; Zazaza, Venter, & Sibiya, 2018). This approach forces the user to accept the services' PP and T&Cs to gain access or to decline these conditions and to not use the service – more latterly known as the "clickwrap agreement" (Obar & Oeldorf-Hirsch, 2020; Obar & Oeldorf-Hirsch, 2016).

Faden and Beauchamp (1986) propose that five core elements of consent are required for individuals to be truly informed, these include: 1. disclosure, 2. comprehension, 3. voluntariness, 4. competence, and 5. consent. Comprehension and significance of disclosure, as well as voluntariness, are difficult criteria to fulfil in terms of supporting users in their provision of eConsent in an online environment (Bashir, Hayes, Lambert, & Kesan, 2015). Carolan (2016) proposes a move away from presumed consent and informed consent to active consent whereby user consent is both interactive and tailored. Users signify their consent by positive action having been informed on what that action represents. However, users are hampered by heuristics that may result in individuals basing their decisions on whatever information is readily available rather than basing decisions on relevant information (Baddeley, 2012). Reading an agreement is essential to understanding it, with many users not reading the PP and T&Cs. This can result in an uninformed choice being made (Obar & Oeldorf-Hirsch, 2016). Voluntariness can also be hindered by the nature of these online agreements which are adhesion contracts, the "take it" or "leave it" basis (Bashir et al., 2015).

The "clickwrap agreement" presented by online services may fail to notify users of the eConsent process. Clickwrap agreements also imply that eConsent is unimportant and discourage users to engage with the eConsent facts (Obar & Oeldorf-Hirsch, 2016). The current online design of eConsent suffers because it lacks clarity in understanding and choice for the user, making decisional autonomy difficult to achieve. With the idea of decisional autonomy being based on the premise that individuals use truthful and relevant information to come to a decision free from coercion, it would seem that

the current online environment of eConsent is wrought with problems (Assale et al., 2019; Feldman, Kumar, Pugliese, Mateo, & Kachnowski, 2019; Iwaya et al., 2019; O'Connor, Rowan, Lynch, & Heavin, 2017; Wright, 1987).

There remains a dearth of research pertaining to the design and development of eConsent (Assale et al., 2019; Doerr et al., 2017; Hochhauser, 2015; Iwaya et al., 2019; Lindegren et al., 2019; O'Connor et al., 2018; O'Connor et al., 2017; Wilbanks, 2018; Zazaza et al., 2018). More specifically, there is a need to embed ethical aspects within the design of eConsent (Wilbanks, 2019). The objective of this study is to explore the factors which impact decisional autonomy when electronically consenting to PP and T&Cs on Health Social Networks (HSNs), a relatively new social networking phenomenon. By taking an exploratory approach, our aim is to elicit a better understanding of user interaction with eConsent. Using Endsley's (1996) theory of Situation Awareness (SA), this article offers insights into the 'As-Is' decisional autonomy of HSN users and how their comprehension, perceptions, and projections impact their decision to provide eConsent.

2. MODEL DEVELOPMENT AND RESEARCH QUESTIONS

Based on existing research in the area of human decision making and intention behaviours, this research utilises Endsley's (1995b) theory of Situation Awareness (SA) as a basis for understanding the causes of decision error to improve safe decision making (Singh, Petersen, & Thomas, 2006). We considered alternatives including Sensemaking (Klein, Moon, and Hoffman, 2006) and Mental Models (MMs) to better understand user decision autonomy. Sensemaking is motivated by a continuous effort to understand connections (which can be among people, places, and events) to anticipate their trajectories and act effectively over time (Klein, Moon, and Hoffman, 2006). While a Mental Model approach is based on logical reasoning which people use their models to infer relationships, predict outcomes, understand the systems they encounter, determine a course of action, control that action, and experience events 'by proxy' (Johnson-Laird, 1983). Endsley's (1995b) SA framework was selected for this study as it supports a user-centered approach at the level of the individual focusing on tactical decisions in the short term.

The SA model is a useful vehicle to explore users' decision making processes at an individual level, see Figure 1. When users are fully aware, SA may be leveraged by users to interpret situations and support them to pursue a more informed approach to decision making. The SA model can enhance user cognition and subsequently support decision making processes (Guimond, Sole, & Salas, 2009). More recently, the interplay between regulation (i.e. GDPR), and technology requires that user be aware, understand and subsequently provide their informed eConsent. This model suggests three interdependent levels in decision making – 1. Perception, 2. Comprehension, and 3. Projection (see

Figure 1. Three level model of situation awareness (adapted from (Endsley, 1995a)
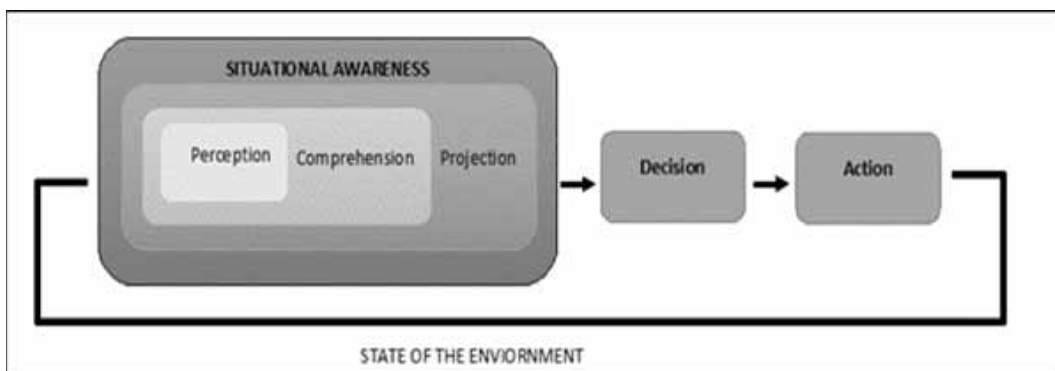
Figure. 1). Endsley (1995b) concludes that a decision is arrived at by successfully integrating these three levels together and then acting upon a decision (Endsley, 1995b).

Endsley's (1995b) description of the different levels within SA consists of Level 1, emphasizing the perception of the elements – the individual perceiving the status, attributes, and dynamics or relevant elements in the environment (Endsley, 1995b). While Level 2 focuses on understanding the current situation – the individual understanding the significance of the elements in the environment (Endsley, 1995b). Level 3 is centered on the information gleaned from Level 1 and Level 2 to support future state of the system and the environment i.e. the ability of the individual making the decision to project the future actions of the elements in the environment. Each of these levels ultimately determine how good overall SA will be in a given situation resulting in a positive outcome, if they are undermined by challenges from within the person and/or within the environment a negative outcome is envisaged (Endsley, 2016). It is from this combination of levels 1 and 2 that individuals can forecast future states in the situation, enabling them to decide and act on this decision choice.

2.1 Analytical Framework

We leverage the SA framework to identify the eConsent elements that are important to individuals. Decisional autonomy results when individuals make the voluntary decision to furnish eConsent on HSNs - PPs and T&Cs (Figure 2). The provision of eConsent results in the sharing of PHI. Awareness is the prerequisite of comprehension that requires individuals are aware that they are undertaking a certain activity (Endsley, 2016) (i.e. that they are consenting to a PP and confirming they have read the policy). Both privacy concern and technical protection explore the phenomena of the 'privacy paradox' – the reasons behind acting differently to predicted verbalisations of behaviour (Teles, e Silva, & Endler, 2017). Norberg, Horne, & Horne (2007) propose that the difference between what individuals say they will do against the actions they take are driven by diverse factors. Intention behaviors being driven by risk assessment, and behavioral action guided by the evaluation of environmental cues i.e. trust (Norberg et al., 2007).

In this study, the privacy paradox is assessed by looking at the degree to which individuals are worried about the possible online security and privacy risks, against whether they take steps to safeguard against these risks. Satisfaction with policy is understood as the participants' satisfaction with the key terms of the PP and associated T&Cs. Decisional autonomy refers to the evaluation of the decision outcome (Endsley, 1995b) i.e. determining if individuals were satisfied that they made the voluntary decision to consent/refuse the HSN privacy policy and terms and conditions.

Figure 2 illustrates the integrated SA model, this adaptation is the basis for understanding individuals' decision making process when providing eConsent on HSNs. Adopting SA to the area of eConsent 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 (Wicks et al., 2010).

Four hypotheses are posed to investigate the conceptual model presented in Figure 2. First, the PP and associated T&Cs on HSNs are frequently subject to change (Steinfeld, 2016). This creates a dynamic environment in which HSN users must maintain awareness. With HSNs retaining the right to change their policies at will, there is an increasing burden on the user to read the PP and T&Cs more than once (Nissenbaum, 2011). Anecdotal evidence suggests that users are not aware of the HSNs business model of selling aggregate data and the possibility of re-identification, despite users consenting to privacy policies that explicitly state these terms. Angwin (2014) documented the case of the media research firm Nielson Company. This company was responsible for scraping private messages from several closed forums on a HSN and selling the raw data to various companies including pharmaceutical companies. While the violation upset users, it was the revelation that HSNs were also selling user data to third party companies that distressed users, as some claimed to be completely unaware of this activity and subsequently deleted their accounts. Yet, the more users are aware of the

Figure 2. The adapted SA model (Endsley, 1995a) with eConsent on HSNs
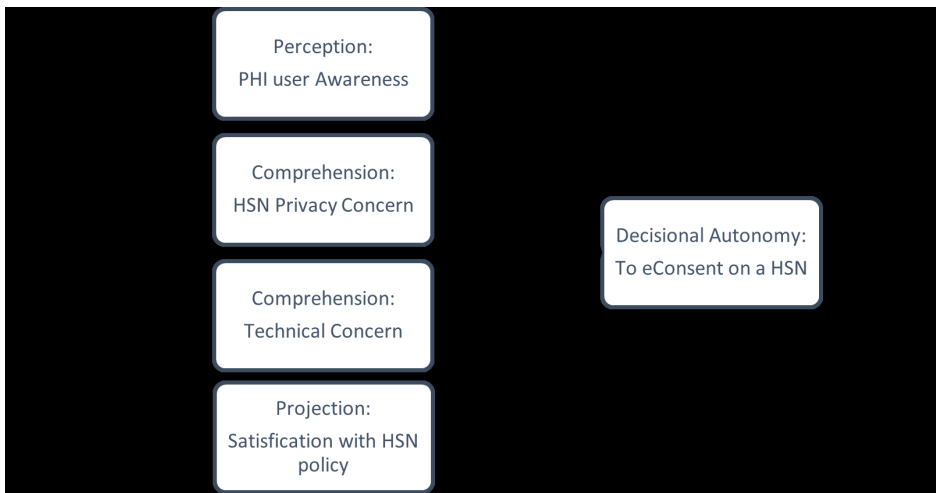
PP and T&Cs (i.e. how their information is handled), the more they engage with social networking sites (Krasnova & Veltri, 2010). Therefore, it is hypothesised that:

H1: PHI user awareness is positively associated with the decisional autonomy to consent/ refuse to consent to a HSN privacy policy and terms and conditions.

It could be claimed that users' expectation of data privacy is unrealistic given the online environment (Cushman, Froomkin, Cava, Abril, & Goodman, 2010). For instance, some HSN users who are aware of the risks to informational privacy share their PHI in the hopes of improving their personal health (Li, 2013). The discrepancy between users' expectations and reality could be influencing users' willingness to share their PHI online (Williams & Weber-Jahnke, 2010). Yet, there is widespread concern that sensitive, high-risk information, i.e. Personal Health Information (PHI), when disclosed could potentially cause stigma, discrimination or even harm (Asiri, Asiri, & Househ, 2014). A real risk of re-identification exists whereby advanced search and informational retrieval techniques can be used by adversaries to aggregate enough online information about an individual to re-identify them e.g. a member of a HSN using the same email address for both their HSN account and professional LinkedIn account (Li, Zhou, Chu, Araki, & Yoshihara, 2011; Faresi, Alazzawe, & Alazzawe, 2014). Therefore, it is hypothesized:

H2: Users' privacy concerns are negatively associated with the decisional autonomy to consent/ refuse to consent to a HSN privacy policy and terms and conditions.

Research states that where there is too much cognitive effort involved in human comprehension and judgement prior to decision making, there is potential for individuals to take Kahneman's (1973) route, that which requires the least amount of effort. With online platforms and eConsent there are a number of factors that may influence this behavior e.g. text being illegible, time pressures to decide, or individuals not being technologically savvy (Hochhauser, 2015). It is argued that these issues converge to produce Kanhneman's law of least effort, if there are several ways to reach a goal people will choose the one that requires least effort (Hochhauser, 2015). If people are struggling to navigate the device and/or too much information, it's likely they will skip the process and consent without any

understanding of the terms. It is also suggested, that the use of fake profiles is used to circumnavigate issues surround privacy and security on social network sites (Olteanu, Huguenin, Dacosta Petrocelli, & Hubaux, 2018). Therefore, it is hypothesised that:

H3: Users' technical concerns are negatively associated with the decisional autonomy to consent/ refuse to consent to a HSN privacy policy and terms and conditions.

The value of PHI along with the risk of sharing such information can mean that many HSN users are unaware of the potential dangers for their data. Williams and Weber-Janke (2010) argue that in comparison to the leakage of financial information, there is no set method to compensate a person for unauthorised use and disclosure of their PHI. It has been suggested that a more holistic approach to the creation of privacy regulations would improve this situation i.e. increase awareness, educate users, and improve the design and regulation of these services (Li, 2013; Pool, 2012). If a framework that adheres to all these aspects of privacy is in place, then users may be satisfied to provide their eConsent to an HSN. Therefore, it is hypothesised that:

H4: Users' satisfaction with the HSN privacy policy positively associated with the decisional autonomy to consent/ refuse to consent to an HSN privacy policy and terms and conditions.

The remainder of this article is structured as follows: the research methodology is described, then the findings from the observation/survey of registration action and focus group discussions are presented. Finally, the conclusions and opportunities for future research are considered.

3. MATERIALS AND METHODS

An exploratory sequential mixed-methods approach (quantitative survey followed by qualitative focus groups) was undertaken for this first phase of a larger funded research project. The rationale for mixing both types of data within one study is grounded in the fact that individually neither quantitative nor qualitative methods are sufficient to encapsulate the trends and details of a situation (Ivankova, Creswell, & Stick, 2006). The exploratory design offered the opportunity to understand the complex interactions of the topic under investigation (Pluye & Hong, 2013). The quantitative element revealing the causal relationships and the qualitative element revealing the causal processes (Seawright, 2016). This study comprised a two-step process – Step 1 required participants to complete an existing HSN registration page using a mock profile, provided by the research team. Whilst completing this process participants were observed by members of the research team, who used an observation checklist to record participant action. At the end of the registration process, participants were asked to complete a survey. Step 2 included participants in focus group discussions, where the research team used a question guide to direct the sessions.

Step1 Details: Direct observation of registration behaviours was deemed relevant to record device usage, participant choice, and action-behaviours. With observational methods there is always the potential for experimenter effects having an influence over participant behaviour. The possibility for experimenter effects were acknowledged, but it was important to include this approach to ensure that registration actions (including the provision or refusal of eConsent) were completed (Salovaara, Oulasvirta, & Jacucci, 2006). To test the conceptual model (see Figure 2), a quantitative survey was designed using a web survey platform, SurveyGizmo. This online survey was constructed using previously validated indicators (APPENDIX C). Responses were captured using a structured approach and 5-point Likert Scale whereby participants were asked

to rate each statement on a Likert Scale with responses ranging from "Strongly Disagree (1)" to "Strongly Agree (5)."

Step2 Details: After volunteering to participate in step 2, three separate focus groups were held, and these took place immediately after participants completed Step 1. The focus group approach was adopted to provide the opportunity for researchers to gain a richer understanding of the eConsent process and to explore the "how" and "why" questions in this research. Focus groups have long been held by researchers to gain insight into human behaviors – individuals sharing their stories, thoughts and emotions on a plethora of topics (Krueger & Casey, 2000). The questions for the focus groups were based on an adaptation of Endsley's model of SA, and looked at four main categories of detail: 1) Perception – participant awareness of eConsent, 2) Comprehension – privacy and security concerns for PHI following eConsent, 3) Projection – satisfaction with the PP and T&Cs following eConsent, and 4) Decision Autonomy – the provision of eConsent on the registration page.

3.1. Sample

We targeted graduate students and young professionals to engage in this study.

Step 1: A total of 53 participants participated in the online survey. From the 53 responses, 50 surveys were usable for data analysis. This sample size is deemed apt for testing the model as the sample size is equal to the larger of (i) ten times the number of indicators on the most formative construct, or (ii) ten times the largest number of antecedent constructs leading to a dependent latent variable (Chin, 1998). Due to the sample size, Partial Least Square [PLS] (Structural Equation Modelling [SEM]) was employed to analyse the data. This approach uses component-based estimations and allows simultaneous examination of both the measurement and the structural models (Hair, Hult, Ringle, Sarstedt, & Thiele, 2017; Hair, Ringle, & Sarstedt, 2011; Hair, Risher, Sarstedt, & Ringle, 2019). The measurement (outer) model represents the relationships between a construct and its associated variables (measurement items) whereas the structural (inner) model represents direct and indirect unobservable relationships among constructs (Diamantopoulos & Siguaw, 2006). SmartPLS was utilised to generate the statistical outputs associated with the survey data.

Step 2: Twenty four participants engaged in the qualitative focus groups. Guest, Namey, and McKenna (2017) purport that two to three focus groups identify 80 percent of the themes and after that the identification of additional new themes is marginal. Three focus groups were held, participant numbers at these were 10:8:6 respectively. There was scope to sample beyond this target if the research team believed the themes had not been fully explored.

Participants' ages ranged from 18 to 44 years, most participants were aged between 25 to 34 years. The gender mix was Male 3:1 Female ratio. The labelling of responses was in line with the collection of data at sessions. Participant responses were labelled as follows: Focus Group One: FG1, Focus Group Two: FG2, and Focus Group Three: FG3. Group responses have been labelled as – General Response or GR. The gender of participants in each group is simply represented by the label of M or F followed by a participant number.

3.2. Materials

A mock profile (Appendix A) was provided to participants for the registration process, which participants used to gain access to the registration form that asked for consent. Participants could then decide whether to provide eConsent or not. An observation check list was used to record participants' behaviors during Step 1 (please see Appendix B for an example). This checklist collected data on the amount of time it took the participant to read either or both the PP and T&Cs, and time taken to provide eConsent. An online survey was employed in Step 1 of the study (Appendix C). A semi-

Table 1. Internal consistency reliability test

	Cronbach's alpha	**Composite reliability**	**Average variance extracted (ave)**
Decisional autonomy	0.882	0.918	0.739
Perception	0.938	0.954	0.807
Privacy concern	0.859	0.898	0.639
Satisfaction with policy	0.762	0.846	0.580
Technical protection/concern	0.724	0.829	0.549

structured interview guide was used by researchers during focus group discussions for Step 2 (see Appendix D) exploring awareness of eConsent, comprehension of privacy and security issues for PHI data, the implications for their PHI data and whether decision autonomy was achieved. Two mobile phones were used during focus group discussions to record data, and these details were then transcribed verbatim. All data was anonymized at source.

3.3. Ethical Approval

Ethical approval for this research was granted by the Social Research Ethics Committee at University College Cork.

4. RESULTS

From the observation of individuals at time of registration it was apparent from that very little time (less than one minute) was spent by participants when providing eConsent. This included finding the agreement checkbox, sourcing, reading, and understanding the PP and T&Cs. From these observations of individuals' behaviours, it can be concluded that few, if any of the participants actually spent time reading and understanding these statements.

4.1. Survey Results

The conceptual model examined during this phase of the research study is measured reflectively (Diamantopoulos & Siguaw, 2006). Reflective item indicators do not define the construct but instead, are manifestations of the construct (Petter, Straub, & Rai, 2007). Reflective indicators represent the same phenomenon (the reflective construct) and thus should be highly correlated (Andreev, Heart, Maoz, & Pliskin, 2009; Jarvis, MacKenzie, & Podsakoff, 2003). Therefore, if the construct was altered, changes are also observed in all measurement items simultaneously. Moreover, reflective measures are interchangeable and dropping one of the measures does not change the meaning of the construct (Joseph F Hair et al., 2019).

4.1.1. Measurement Model Evaluation

The measurement model was assessed in terms of reliability and validity. Reliability of construct measurements was evaluated by examining Cronbach's Alpha, Composite Reliability, and Average Variance Extracted. As depicted in Table 1, all evaluations exceed the thresholds values of 0.7, 0.6 and 0.5 respectively.

Individual reliability examines determinant loadings by specifying which part of an indicators' variance can be explained by the underlying latent variable (Chin, 1998). For this study, the threshold cut-off value for individual reliability is 0.707. Any indicators following below this threshold were removed from the study (see Table 2 and Appendix C).

Latent variable cross loadings were used to assess convergent validity and discriminant validity. Convergent validity is shown when each measurement item correlates strongly with its assumed theoretical construct. Therefore, AVE must equal or exceeds 0.5. As shown in Table 1, AVE values are higher than 0.5 indicating sufficient convergent validity. When each measurement item correlates weakly with all other constructs except for the one to which it is theoretically associated, then discriminant validity is shown (Gefen & Straub, 2005). Using the Fornell and Larcker (1981) approach, the AVE of a determinant must be larger than the squared correlation of this determinant with any other determinant. Noteworthy, however, the Fornell and Larcker criterion has to be assessed manually

Table 2. Item Cross Loading

	Decision autonomy	Privacy concern	Perception	Satisfaction with policy	Technical protection/ concern
Da1	**0.912752**	-0.42208	0.674832	-0.33277	0.584068
Da2	**0.891883**	-0.25357	0.526659	-0.36761	0.469574
Da3	**0.708178**	-0.04813	0.363147	-0.142274	0.34295
Da4	**0.90948**	-0.27273	0.624123	-0.360319	0.41832
Pc1	-0.145298	**0.758217**	-0.248593	-0.125206	-0.46025
Pc3	-0.363432	**0.910383**	-0.287872	-0.016109	-0.49873
Pc6	-0.223019	**0.798928**	-0.192822	-0.00965	-0.36073
Pc7	-0.178505	**0.730154**	-0.366451	0.195778	-0.35517
Pc8	-0.265786	**0.787089**	-0.249827	0.115603	-0.32644
Per1	0.661612	-0.20328	**0.738541**	-0.269015	0.396043
Per2	0.546863	-0.30563	**0.930768**	-0.334643	0.562015
Per3	0.611504	-0.32984	**0.949567**	-0.366562	0.626171
Per4	0.507952	-0.32341	**0.917374**	-0.341367	0.547006
Per5	0.568336	-0.31833	**0.939097**	-0.379819	0.591217
Sp1	-0.338388	-0.09144	-0.213831	**0.788794**	-0.00054
Sp2	-0.27114	0.053905	-0.384509	**0.759063**	-0.19828
Sp3	-0.238484	0.100991	-0.332291	**0.714211**	-0.32308
Sp4	-0.241174	0.109788	-0.242304	**0.781522**	-0.17585
Tp1	0.384004	-0.22115	0.556921	-0.32077	**0.698211**
Tp4	0.42401	-0.3759	0.504512	-0.031488	**0.713806**
Tp5	0.370979	-0.42044	0.359218	0.005983	**0.810274**
Tp7	0.408514	-0.45286	0.369656	-0.269545	**0.736137**

as it is not automatically calculated by the applied software SmartPLS. Table 3 shows all constructs have sufficient discriminant validity. Cross loading of individual items is presented in Appendix C.

As all criteria are fulfilled, the measurement model is regarded as reliable and valid, which is a necessary condition for a valid assessment of the structural model.

Table 3. Cross Construct Discriminant Validity

	Decisional autonomy	Perception	Privacy concern	Satisfaction with policy	Technical protection/concern
Decisional autonomy	0.86				
Perception	0.81	0.899			
Privacy concern	0.56	0.57	0.799		
Satisfaction with policy	0.60	0.61	0.2	0.761	
Technical protection/concern	0.73	0.78	0.71	0.46	0.741

4.1.2. Structural Model Evaluation

Analysis of the structural model allows us to accept or reject each hypothesis as well as understand the actual contribution that an independent variable makes in explaining the variance in a dependent variable (Hair et al., 2019). The four hypotheses presented in Table 4 were tested by employing the bootstrapping re-sampling technique. Since larger numbers of resamples lead to more reasonable estimates of standard error (Tenenhaus, Vinzi, Chatelin, & Lauro, 2005) the bootstrapping procedure was undertaken with 500 samples to produce stable results. This was performed to calculate the corresponding t-values for each path, in order to assess the significance of path estimates (Table 4).

Effect sizes were determined by comparing the explained amount of variance when a predictor

Table 4. Path coefficients, significance levels and hypotheses outcome

Association	T statistic	P values	Outcome
Perception – decisional autonomy	3.233	0.001	H1 supported
Privacy concern – decisional autonomy	0.453	0.651	H2 not supported
Technical protection/concern decisional autonomy	1.225	0.221	H3 not supported
Satisfaction with policy – decisional autonomy	1.290	0.196	H4 not supported

is either included or not included in the model, that is, $f2 = (R2incl – R2excl)/ (1 – R2incl)$. f^2 values of 0.02, 0.15, and 0.35 signify small, medium, and large effects, respectively (J Cohen, 1998; Cohen, Cohen, West, & Aiken, 2013). Overall, the conceptual model has a medium effect (see APPENDIX D).

4.2. Focus Group Results

Focus group results were analyzed following the SA framework (see Figure 2). The findings are grouped into four themes: 1) Perception Awareness; 2) Comprehension: Privacy Concern; 3) Comprehension: Technical Protection; and 4) Projection: Satisfaction with Policy. The clustering together of ideas conformed to these four themes.

4.2.1. Perception Awareness

Data collected from focus group discussions illustrated that participants were working on 'automatic pilot', not looking for the information on eConsent at the time of registration. Instead, participants unconsciously consented by simply 'ticking agree' (Table 5). Participants suggested that based on their

Table 5. Participants' views on automatic behaviors

Participant id	Participant comment
Fg3:m2	"i just ticked the box"
Fg2:m4	"i just didn't think of it, i just ticked the box and away i went."
Fg2:m2	"they (pp and t&cs) are not written to be read"
Fg1:gr	"they (pp and t&cs) are too long, too complicated"

previous experiences engaging with these documents, they found them to be written in a language that was hard to decipher and simply not user friendly. This was further hindered by the screen size of the mobile devices (i.e. those who used smartphones when registering on the HSN), often requiring the users to continuously scroll through jargon-filled content.

4.2.2. Comprehension – Privacy Concern

Participants expressed concerns about the privacy of their health data including issues surrounding hacking, identity fraud, and tracking of online behaviors to discrimination by third parties. Table 6 provides illustrative comments on these points made during the focus group discussions. Privacy concerns vis-à-vis the potential implications of PHI data use by 3rd parties arose among participants arose during the group discussion. Whether these privacy concerns would have a negative impact on decision autonomy in the future is difficult to predict. Recognition of these privacy concerns are required by users. This means being consciously aware of these issues at the time of providing eConsent. Automatic behaviours seemingly acted as an impediment to a participant's reasoning process.

Table 6. Participants views on their privacy concerns

Participant id	Participant comment
Fg1:m5	"what happens if they get hacked or something goes wrong, or if someone working in the company decides to, you know, capture all the information and sell it on, there is no real security is there?"
Fg1:m3	"i think people are unaware, i think people have never had identity fraud happen to them, so maybe if that had happened to you, you would have a different attitude."
Fg2:m5	"the problem is tracking your life in real-time and making decisions in real-time what you will do in the future."
Fg1:f1	"it's just if those would go against you in future, like, buying insurance, or you can't get insurance because … you have medical issues."
Fg1:m5	"employers might discriminate, or health insurances definitely will…"

4.2.3. Comprehension – Technical Protection

It was uncovered that some participants were willing to create dummy accounts to overcome issues surrounding their privacy concerns. The idea of using a personal rather than professional email was common amongst participants; however, the follow-up step of using fake names would only become a consideration when there were concerns about the use of their data by a HSN service. Furthermore, a lack of technological know-how was evident in discussions, many not realising how their health

Table 7. Participants views on the technical aspects of eConsent

Participant id	Participant comment
Fg3:m3	"not an email that you would use for work. I wouldn't put my real email in there"
Fg1:m5	"if you were worried about your data, i'd just use a fake name, user name, fake email address, and like you could be identified with, that would be one way around it."
Fg2:m3	"i think in that case (if you are worried about registering for a hsn) that perhaps you would use a fake profile."
Fg3:m3	"i wouldn't even consider giving them a fake name, i would have just given them my real name."
Fg1:m2	"i think it would be better if you could also see who's viewed your profile, who's viewed what health problems you have … if you can't see who viewed your profile, you don't know … who knows what health problems you have."
Fg2:m3	"if i was setting up a profile though i wouldn't be telling people that i was on medication on the website. I wouldn't want people knowing that information on me, out there for everyone to see."
Fg2:m5	"on social sites, health profile is just one component of your profile that big companies are using."
Fg3:m5	"most people don't even know what cookies are."
Fg3:m3	"whereas cookies, it would be better if you had to click through each one of these and say "okay, i've acknowledged that my data is being used."

Table 8. Participants views on policy satisfaction

Participant id	Participant comment
Fg1:m1	"once my identity, name is lost (de-identified on the hsn), that's okay.
Fg1:m3	"i think we can't just understand the cost, you get, you know if your identity was stolen."
Fg2:m2	"they ask personal questions, … the questions are very, very personal, even your name, your surname, i think they are very interested in your personal identity, so it's not about sharing your data."
Fg3:f1	"you wouldn't want any third party having access to your data."
Fg3:m2	"i can't think of a good third party."
Fg3:m3	"i don't really understand what a lot of them (3rd parties) would use my phi for, i'm just not that happy about it."
Fg1:m4	"it is just the fear of what will happen to me, my data, would make me hesitant."
Fg1:m2	"i don't think i'd sign up for it because you don't know what they are going to do with your data."
Fg3:m2	"you have no control, as soon as you tick the agree,"… and … "you feel like you can't control your data.
Fg3:m1	"i'd like to have more control over it (phi – like on facebook) and see … how others see my profile, to be honest."
Fg3:f1	"i do think they could give you some level of security and you can manage it yourself easily."

data could be accessed by synchronising from one platform to another, or the function of cookies to track/trace, and how to control the level of profile access other users might have (see Table 7).

Table 9. Participants views on decision autonomy

Participant id	Participant comment
Fg1:f1	"now knowing the pp and t&c of the hsn has definitely changed my decision to join."
Fg1:gr	"we would not be happy with our data being accessed."
Fg1:m4	"for me it is still the issue of who's behind this website,… it's the commercial interests that make me more concerned."
Fg2:f1	"i would not be happy to share my medical information."
Fg2:m3	"i would not be happy to join that site with my personal information being identified."
Fg3:m1	"oh, yes, i wouldn't sign up to a hsn."
Fg3:m4	"i regret agreeing to the pp and t&cs."
Reasons to join hsns:	
Fg2:m2	"i think if someone has a serious illness that is not finding a solution very easy"
Fg2:m6	"if you had a serious condition," . . . And . . . "to get information on clinical trials or something, that would give you hope, then it might be useful."

4.2.4. Projection – Satisfaction with Policy

When participants became aware of the potential use and sharing of their data, they openly expressed their concerns. Issues were raised regarding the amount of personal information collected, their identity and diagnosis/medication history – reflecting that they indicated that would move to delete their accounts based on this knowledge. Participants suggested improving the level of control users had over their PHI by offering user choice over security/sharing levels and referring to the system setup on other sites such as Facebook (Table 8).

4.2.5. Decision Autonomy

It was during focus group reflections that expressions of dissatisfaction with decision autonomy were articulated by participants. Decision autonomy was represented as participants' views on whether they were happy or unhappy about the key details within the PP and T&Cs. Participants indicated that they would change their decision to join as they were unhappy about their data being accessed and shared, regretting their decision to register with this service.

The benefits of joining HSNs for individuals with illnesses were acknowledged by focus group participants, especially when individuals with serious conditions continue to search for answers and seek support from others. For the participants the negative aspects in the details of the PP and T&Cs were disconcerting (see Table 9).

5. DISCUSSION AND LIMITATIONS

This research explores the factors which influence an individual's decision autonomy when providing electronic informed consent (eConsent) to a Health Social Network (HSN). While research has vastly documented the informed consent process, this has predominantly been paper-based and in a clinical setting (McKinney Jr et al., 2015). According to O'Connell (2016, p. 68) "the explosion of big data and digital information has transpired with little attention to ethical considerations of consent,

privacy, and confidentiality". This article highlights this issue and provides some insights for HSNs, so they can inform users on how their personal data is accessed, managed, and used at the time of registration. We use Situated Awareness as the analytical framework to understand participants' decision making processes.

Four hypotheses were posed and explored as part of this research. The findings to support H1 (Awareness is positively associated with the decisional autonomy to consent/ refuse to consent to a HSN privacy policy and terms and conditions) are mixed. Based on the quantitative data the findings support this hypothesis. This finding aligns with existing research that states that rational decision making in conjunction with situational assessments allow individuals to make a rational choice to take an action (Hernstein, 1990). Yet, there is evidence of post-hoc rationalisations for actions and one cannot discount the external influence of group processes impacting on behaviours observed at the time of consent. This occurs when participants are not fully engaging with the background details of consent and they follow the herd assuming safety in proceeding (Bashir et al., 2015; O'Connor et al., 2017). The difference between this instantaneous behaviour and expressed later regret at taking this action conforms to ideas presented elsewhere that decisions are influenced by a multitude of factors including social, cultural, emotional, personal contexts (Felt et al., 2009).

The fact that our qualitative focus-groups findings disagree with the quantitative results aligns quite closely with existing ideas around nudges and individuals falling into default actions, irrespective of whether this is the best choice for them at the time (Epstein, 2017). A prime example of this is the privacy paradox. Our research discovered the privacy paradox in practice. Survey and focus group discussions illustrate contradictory reporting, due to participants' online eConsent behaviour being based on instinct which was hampered by heuristics and biases. The focus group discussions were responses based on reasoned and deliberate self-reflection. The discrepancy between the privacy preferences described and how participants acted supplied evidence of the privacy paradox in practice (see the work of Kahneman (2011)). It is also relevant to recognise that during the focus group sessions the content of the PP and T&Cs were discussed and there was also potential for biases such as social desirability or demand characteristics to influence responses (Neuberger, 2016). The reason for the overall mixed support for the hypotheses might be impacted by the social desirability of survey responses as opposed to focus group discussions. It is very possible that participants listened to others in the focus group and expressed some consensus of opinion, a shared mental model of sorts (Converse, Cannon-Bowers, & Salas, 1993). Yet, times of social conformity were offset by power equality and the freedom to express differing opinions. Focus group discussions allowed for the free flow of reflection on the implications of eConsent and the terms of engagement, unavailable at the time of survey completion

From exploring participants' behaviours, it became evident that most users had a low level of awareness about the provision of their consent when joining a HSN. It was observed that these participants worked on 'automatic pilot', they did not engage in eConsent fact finding i.e. reading and understanding the PP and T&Cs. The habitual nature of automatically selecting the checkbox for consent initially had no impact when users decided to register to the HSN. Our findings are in line with prior research purporting that online users do not read notices or heed warnings because of habituation (Böhme & Köpsell, 2010). This habituation of behaviour is caused by the design of online check boxes and other form objects, which compel the user to just get tasks done to access services. This conduct is also applied to critical factors such as privacy and security (Böhme & Köpsell, 2010). However, upon reflection of the content in the PP and T&Cs most users acknowledged they would consider reviewing the PP and T&Cs more carefully in the future. Yet, there needs to be an easier way to reveal the hidden complexity associated with the PP and T&Cs (Lugar, Moran & Rodden, 2013; Tabassum et al., 2018). Failure to simplify the process will ultimately result in users maintaining their habitual routines of automatically selecting 'agree' without fully understanding the contents within the PP and T&Cs (O' Connell, 2016).

H2 (Privacy concern is negatively associated with the decisional autonomy to consent/ refuse to consent to a HSN privacy policy and terms and conditions) and H3 (Technical protection is negatively associated with the decisional autonomy to consent/ refuse to consent to a HSN privacy policy and terms and conditions) focuses on comprehension. This study found that both hypotheses were not supported by the quantitative data, yet they are supported by the qualitative data.

Building from H1, without reading the consent statements individuals' judgement was affected. It follows that as an extension of the privacy paradox in practice, participants initially reported they felt no concern over privacy and technical issues and later in discussions they expressed concern about this, using post-hoc rationalisations for their increased awareness (Summers, 2017). 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 they have read that policy (Endsley, 1995b). Participants' decision making suffered from a lack of comprehension in terms of both the privacy and technical agreements provided by this service. PHI, is by its nature sensitive and, is classed as high-risk information that if improperly disclosed could cause embarrassment, stigma, discrimination and in extreme cases physical harm (Asiri et al., 2014). Given that sharing PHI online is high risk, it is reasonable for users to have certain expectations around data privacy, including controlling what information they share, who sees it and how it is used, however these expectations are often unrealistic given the online environment (Cushman et al., 2010; Li, 2013). If privacy breaches occur there is no legal accountability. While some HSNs make efforts to adhere to the HIPPA (Health Insurance Portability and Accountability Act, 1996) they are not legally obliged to, as users are voluntarily providing the HSN with their PHI (Li, 2013). When data is stored in the cloud, a user's country or state health and/or consumer laws also offers no protection given the difficulty in establishing legal jurisdiction where "data possession", "custody" and "ownership" can be challenged (Deb & Srirama, 2013). The findings reveal that without engaging in levels 1 and 2 – perception and comprehension of situation awareness - that participants' satisfaction with the decision at level 3 would be negatively impacted (see Figure 3).

Figure 3. The integrated SA model (Endsley, 1995a) and analysis of eConsent
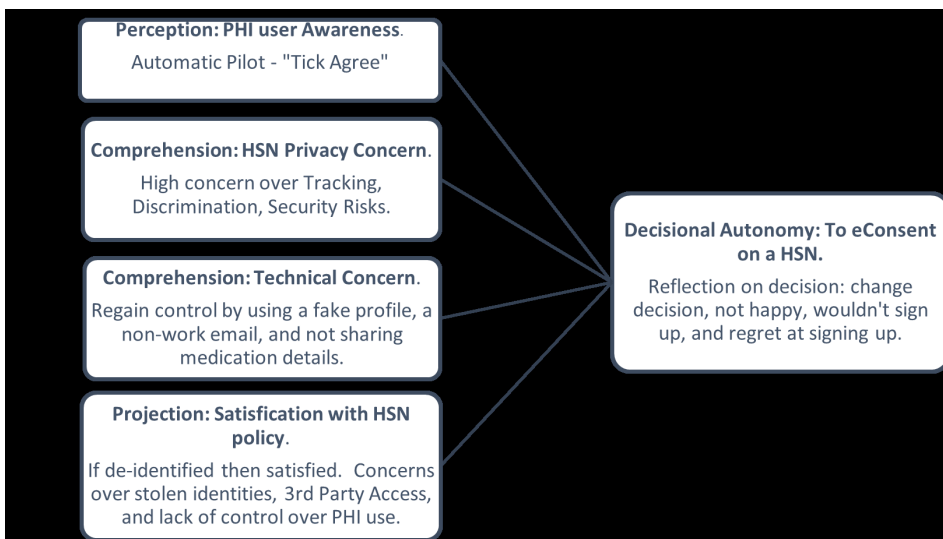
H4 (Satisfaction with the HSN privacy policy is positively associated with the decisional autonomy to consent/ refuse to consent to a HSN privacy policy and terms and conditions) is not supported by the quantitative findings but is supported by the qualitative data. Interestingly, satisfaction with online eConsent decisions has been found to be closely associated with the educational level of participants, expressly the more highly educated the participant the greater their dissatisfaction (Raz et al., 2020). It is unsurprising that participants reported contradictory results on their satisfaction levels in the survey and focus group elements. At the time of survey completion participants had not engaged with the PP, so therefore they could not express satisfaction. It was not until the focus group discussions that the details of the PP were truly interrogated by participants. During the discussion they could air their dissatisfaction/satisfaction with the conditions of engagement they had signed up to.

The three levels of SA offer support for the development of education and training strategies and design guidelines (Salmon et al., 2008). When there are lapses in SA, there is greater potential for decision making deficits. Consideration would also need to be given to other factors such as time pressures which could compromise decision making (Braithwaite, Healy, & Dwan, 2005). The SA model offers a simple intuitive mechanism for exploring the three levels, assisting in a better understanding of the eConsent process on HSNs.

The results from this study contribute to the future development of guidelines for eConsent designers and developers to ensure that when individuals register on HSNs they are doing so with full knowledge of the PPs and T&Cs. The GDPR mandates that data controllers and processors are required to emphasise transparency, security and accountability, while concurrently standardising and strengthening the right of European citizens to data privacy (Data Protection Commissioner, 2018). One of the central principles underpinning the GDPR is to increase citizen awareness surrounding consent for data processing and usage.

This research offers insights into decision behaviours, both in terms of the automatic processing and the inconsistencies between intention behaviors and actual decision choice. The future development of eConsent may involve a different type of media production such as video discussions or short educational talks. eConsent has the potential to be transformed into a highly tailored two-way engagement that understands individuals' needs based on previous internet behaviours, impacting on both intention behaviour and decision action. This research highlights the value of using the SA model as a first step in understanding the decision processes of individuals at the time of deciding to register with a HSN and to provide eConsent, as well as the post-hoc reflection on the decisions made. It clearly demonstrates that without full awareness of the decision situation, the individual will later experience regret at the decision action.

From a practical perspective, this research highlights an opportunity to improve the interconnectedness of the political, i.e. design and development to promote the accessibility of resources PP & TCs from a regulatory perspective, and the technical, i.e. the design of the technical artefact, when it comes to the provision of eConsent on HSNs. Information Systems (IS)/Information Technology (IT) managers play an integral role by embracing a "Privacy by Design" approach to delivering eConsent (O'Connor et al., 2017). IT/IS managers need to understand the ethical and compliance requirements understanding users' needs, determining the regulatory and ethical questions that should be asked and how to effectively embed these as part of the eConsent process. They need to work closely with designers and developers to evaluate, review, and educate stakeholders to understand the rapidly changing digital data privacy and consent landscape.

This study is not without its limitations. We acknowledge the limitations associated with the generalisability of findings in terms of sample size and type of participants. Yet, when undertaking exploratory research, the use of such convenience samples provides a good starting point from which to extend and develop a more rigorous research design for the future. It is about finding a balance between the sample being small enough to manage and large enough to provide new and richly textured understanding of the experience (Sandelowski, 1995). As Glaser (1965) posed when no new themes are found, theoretical saturation has been achieved. A mixture of quantitative and qualitative methods

provides a snapshot into both the causal effects and the causal mechanisms (Seawright, 2016). Like all research, the aim is to estimate the parameters of interest correctly, but this is conducted under constraints such as time and/or project restrictions. Thus, this research is deemed fit for purpose and not perfect (Statistics Canada, 2017). To test the certainty of any findings lies in replication (Selvin, 1958). It is envisaged that the learnings from this exploratory study will assist in promoting and progressing this under investigated area of research.

6. CONCLUSION AND SUGGESTIONS FOR FUTURE RESEARCH

HSNs offer users an opportunity to connect with communities of likeminded individuals and share health data around symptoms, treatments, and lifestyle. This data sharing takes place in an environment that is often perceived as "safe". In the current online environment of implied consent, with the use of 'checkbox' acceptance of PP and T&Cs, users signing up to these HSN services may experience from a lack of awareness about how their PHI could potentially be used. It is apparent from this research that individuals' have concerns around the privacy and security of their health data online.

This study contributes to the existing body of research, we leverage Endsley's SA lens to present a new understanding of user's decision autonomy in the provision of eConsent on HSNs, illustrated in Figure 3. This framework highlights user perceptions, comprehension around technical concerns and privacy concerns, and projections of future consequences and their impact participants' decision autonomy in providing eConsent. This framework could also be used to interrogate user decision autonomy in a number of other scenarios where users are asked to provide consent for the provision of sensitive PHI, for example Covid-19 track and trace mobile applications.

This research supports previous findings relating to the use of 'clickwrap' agreements which are considered to hinder the consent process and imply that consent materials are unimportant (Obar & Oeldorf-Hirsch, 2016; Obar & Oeldorf-Hirsch, 2020). Notably, our participants were operating on 'automatic pilot' when providing eConsent, which resulted in regret expressed during the post-hoc analysis on the details of the PP and T&C statements. Our research adds further value to the existing body of evidence, by emphasising the need to reconsider the form and content of 'clickwrap' agreements by online services, especially when they involve the collection of sensitive PHI.

This research highlights the need to better educate citizens on the importance of understanding the PP and T&Cs associated with sharing PHI on health-related services. From a practitioner perspective, software designers and developers should consider how technological affordances may be leveraged to design an eConsent process that better addresses individual user's data privacy needs at the time of registration. An opportunity exists to create a technologically savvy citizen, to gather information from citizens on their attitudes and perceptions of eConsent and also by improving the availability and quality of information and education about eConsent.

As-is, HSN users may feel vulnerable with perceptions that limited options exist, as they have little awareness or understanding of existing eConsent processes relating to their data, how it is stored, processed, and used. It is possible that alternative presentations of eConsent could eliminate the current problems users face when deciding to register on HSN services, the "one size fits all approach" requires modification.

By understanding the diverse needs of users, designers could move towards a more tailored approach to the eConsent process, one that offers a better fit for user education, accessibility, and usability. Integral to any technical changes are the changing regulatory and compliance requirements. GDPR has impacted how sensitive health data is elicited, stored, analysed, shared, and used. A more tailored eConsent process could update based on an individual's explicitly defined preferences and flex to support the regulatory requirements in an individual's geographic jurisdiction. An interdisciplinary research approach is required to develop a more holistic political-technical approach to eConsent design and development to address the need for eConsent 'clickwrap' agreement reform.

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APPENDIX A – MOCK PROFILE TEMPLATE

Answers to on-screen questions were supplied by Researchers

Mock Profile.
Screen 1: Name: Mary Murphy Email Address: MMurphy@hotmail.com Password: *********** Username: MMurphy1 Type of Condition: diabetes **Screen 2:** Gender: Female Country of Residence: Ireland State/County: Waterford Ethnicity: Caucasian Race: Irish Start Building your health Profile: Health Profile – open ended box: Email Reminders: Please do not select **Screen 3:** The user homepage

APPENDIX B – OBSERVATION CHECKLIST

Observation Check List	
Study ID Number:	
Ticked consent box for 'terms & conditions of use' and 'privacy policy' first time?	Yes/No
If no, ticked consent box for 'terms & conditions of use' and 'privacy policy' second time after being prompted by website?	Yes/No
Read "Terms & Conditions of Use" before registering?	Yes/No
If yes, how long did they spend?	minutes
Read "Privacy Policy" before registering?	Yes/No
If yes, how long did they spend?	minutes
Total duration taken to register?	minutes

APPENDIX C – SURVEY/ITEM DESCRIPTIONS

Variable	Statement:	Item
PERCEPTION (PHI User Awareness)	I was aware of being asked to consent to the privacy policy and terms and conditions as I registered.	Per1
	I read the full privacy policy.	Per2
	I understood the privacy policy.	Per3
	I read the full terms and conditions.	Per4
	I understood the terms and conditions.	Per5
Comprehension (Privacy concern)	My account being hacked.	PC1
	Being asked too much personal information when registering.	P C 1
	Online identity theft.	PC2*
	Advertisers using my personal information so they can better target their ads.	P C 3
	Third party applications gaining access to my personal information.	PC4*
	Information from my account being applied in situations where reputation matters e.g. potential employers, landlords etc.	PC5*
	Social networks tracking where I go after I leave the website.	P C 6
	Privacy policies changing after I create my account.	P C 7
	Malicious malware being unwittingly installed on my device.	P C 8
Comprehension (Technical concern)	I used a strong password different from the passwords I use to access other sites.	TP1
	When asked to provide security questions, I used information that others would not know about me.	T P 2 *
	I did not provide a work-associated email when registering.	T P 3 *
	I did not use my real name, especially my last name as my username.	T P 4
	I familiarised myself with the privacy settings e.g. who can view my personal information.	T P 5
	I didn't share my birthday, age or place of birth.	T P 6 *
	I deleted cookies every time I left the health networking site.	T P 7
PROJECTION (Satisfaction with policy)	The personal health information I share will not be covered by legally binding data protection legislation.	SP1
	It may be possible to discern my identity from the personal health information I share.	S P 2
	It is possible that employers, insurance companies, or others could discriminate against me based on the health information I have shared.	S P 3
	I will have to manually remove the information from my profile and directly contact the website in order to remove my account.	S P 4
Decision (Decisional Autonomy)	I am satisfied that I was adequately informed about the issues important to my decision.	DA1
	I am satisfied that my decision was consistent with my personal values.	D A 2
	I am satisfied that this was my decision to make.	D A 3
	I am satisfied with my decision.	D A 4

* Removed due to poor individual item reliability (i.e. Individual reliability less than 0.707)

APPENDIX D – FOCUS GROUP QUESTIONS

Discussion One – Perception
User's awareness of consenting to the privacy policy and terms and conditions of use and their concerns around consenting to such policies.
Q1 – When you registered for the HSN, how did you find the process of giving consent to the privacy policy and terms and conditions of use?
Prompt 1a: Is consenting to these policies something you did automatically, or would you read them?
Prompt 1b: If automatically, what are some of your reasons for not reading the policies?
Prompt 1c: If you did read them, what motivated you to do so?
Prompt 1d: If you did read them, what issues (if any) did you experience around understanding the policy?
Q2 – Would you say consenting to these policies is something that concerned you?
Prompt 2a: If yes, could you explain what your concerns were?
Prompt 2b: If no, why were you satisfied to consent?
Discussion Two – Comprehension
User's privacy and security issues around their HSN accounts and the level of protective measure they take to secure their accounts.
Q3 – Do you feel there are any issues with the security and privacy of your HSN account?
Prompt 3a: If yes, could you describe some of these issues?
Prompt 3b: If no, what makes you feel that your account is secure?
Prompt 3c: What (if any) additional protections do you use to make sure your account is secure?
Prompt 3d: What additional measures could HSN use to help secure your account?
Discussion Three – Projection
User's satisfaction with the implications that the policies they consent to have for their personal health information.
Q4 – Based on your knowledge from participating in this study about key points in the policies (e.g. who has access to your data and how it is used), do you feel satisfied with the implications these policies have for your data?
Prompt 4a: What aspects of the policy do you feel satisfied with?
Prompt 4b: What aspects of the policy do you feel unsatisfied with?
Prompt 4c: What changes would you like HSNs to make to the policies?
Discussion Four – Decisional Autonomy
User's belief that their decision to consent was autonomous and informed and they would make the same decision again based on their current level of knowledge.
Q5 – Based on your current knowledge of the policies, would you still consent to the HSN policies?
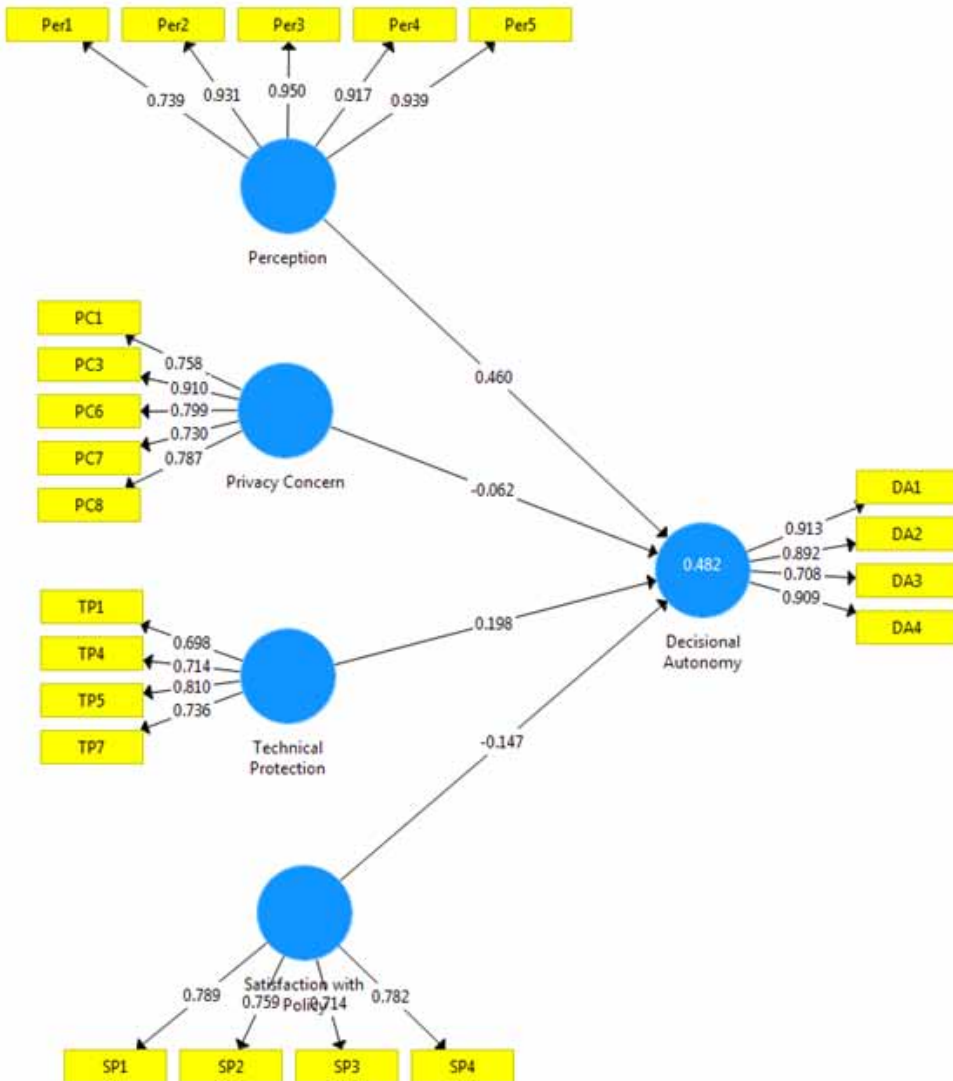**Prompt 5a:** If yes, what are your reasons for consenting?
Prompt 5b: If no, what issues have made you change your mind?

Q6 – What changes (if any) would you like to see in how HSN ask users to give consent to their policies?

APPENDIX D – FOCUS GROUP QUESTIONS

Figure 4.

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