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Title	Exploring user behaviours when providing electronic consent on Health Social Networks: a 'Just Tick Agree' approach
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Publication date	2017
Original Citation	Rowan, W., O'Connor, Y., Lynch, L. and Heavin, C. (2017) 'Exploring user behaviours when providing electronic consent on Health Social Networks: A 'Just Tick Agree' approach', Procedia Computer Science, 121, pp. 968-975. doi: 10.1016/j.procs.2017.11.125
Type of publication	Article (peer-reviewed)
Link to publisher's version	https://www.sciencedirect.com/science/article/pii/S187705091732327X - 10.1016/j.procs.2017.11.125
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Download date	2026-11-07 10:13:04
Item downloaded from	https://hdl.handle.net/10468/5506



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ScienceDirect

Procedia Computer Science 121 (2017) 968–975

Procedia Computer Science

www.elsevier.com/locate/procedia

CENTERIS - International Conference on ENTERprise Information Systems / ProjMAN - International Conference on Project MANagement / HCist - International Conference on Health and Social Care Information Systems and Technologies, CENTERIS / ProjMAN / HCist 2017, 8-10 November 2017, Barcelona, Spain

Exploring User Behaviours when Providing Electronic Consent on Health Social Networks: A 'Just Tick Agree' Approach

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Abstract

In an online world, the distinction between public and private is becoming increasingly blurred with rising concerns about the privacy and security of personal health information. The aim of this study is to explore electronic consent (eConsent) on a Health Social Network (HSN) – PatientsLikeMe - to improve both the form and accessibility of contractual information presented to HSN users. Participants registered on this HSN and their interaction/behaviours was observed when agreeing to the site's Terms and Conditions (T&C's) and Privacy Policy (PP) documents. Focus group discussions were used to help us understand how and why certain events occurred. Several themes emerged from this data - 'Just Tick Agree' phenomenon, perceived societal benefits for the public good, data privacy concerns and emotional drivers towards eConsent. By achieving a deeper understanding of the eConsent process to an HSN, contributions are presented for both theory and practice. We argue that the complex language used for T&C's and PP statements when simplified would increase user knowledge, awareness and understanding. Furthermore, HSN user behaviours (i.e. 'Just Tick Agree') must change when registering on HSNs and, developers of HSNs should enable user choice on registration by changing how users' control their personal health-related data.

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10.1016/j.procs.2017.11.125

Keywords: eConsent; Privacy; Health Social Networks; PatientsLikeMe.

1. Background and Literature Review

A Health Social Network (HSN) can offer users the potential to connect with others, sharing their experiences and learning from each other[1]. When a person registers on a HSN – in this instance PatientsLikeMe - they must provide their name, email address, health condition and identify common medications taken. Once registered, they can continue to build their personal health profile. There are positive aspects of connecting to a HSN including: users can share their health experiences, learn from each other and feel connected to others with similar health issues[2]. Therefore, a HSN such as PatientsLikeMe offers the potential for the user to increase their knowledge and understanding of health conditions[2].

Part of the registration process on PatientsLikeMe involves users confirming that they have read the terms and conditions (T&Cs), and privacy policy (PP) of this site. Ideally when joining, people should check that they are happy with the content of these documents. It is important for users to note that a HSN registered in a specific jurisdiction is governed by that country's data protection laws e.g. in USA, the Health Insurance Portability and Accountability Act (HIPPA 1996)[3] regulates private health information (PHI). Therefore, as HSN users on PatientsLikeMe (registered in the USA) individuals are signing up to the regulatory standards set by the USA. But as an Irish Citizen, joining this HSN, the usual government of health data by – the Data Protection Act 1988 (Amended 2003)[4] – would not apply. Past studies have found that HSN users are not always happy about agreeing to the T&C's and PPs offered on these sites, with concerns about the electronic collection, storage and use of their PHI[5,6]. Yet, according to a survey on people reading company's T&C's, 73% admitted to not reading them at all and of those that did, only 17% understood them[7]. Therefore, users reading the T&C's and PPs of a HSN, where sensitive health information is shared, would be a positive move for users to learn more about their rights and the control of their data. Such a HSN should ideally provide information about the disclosure of users' PHI to third parties, the types of data that is restricted and the exceptions to these restrictions, in addition to when their private data will be shared.

The collection and use of health data beyond clinical care can be considered essential to the enhancement of healthcare experiences, improving health quality and outcomes for the population[8]. The issue of education around informed consent needs to be addressed so that users' knowledge on HSNs is increased and their understanding deepened about the positive aspect of sharing health data[9]. As Rosenbaum et al (pg.1443)[10] states "*An intense struggle over health information access has been a hallmark of the health care system for decades … Opponents raise a host of concerns, citing patient privacy, the confidential nature of the patient/professional relationship, and health information security.*" Thus, sharing health information online has the potential to offer benefits to improve overall health outcomes by harnessing the power of "the crowd"[11].

Of course, there have been instances when patients' healthcare information has been used without their consent by research corporations[12]. One such incident took place in the UK were a deal was struck between DeepMind (an Artificial Intelligence Firm) and the Royal Free NHS London Hospital to develop a clinical app. This app was based on private health information and gave DeepMind access to health data on 1.6 million people[13]. As a result, user concerns about giving electronic consent (eConsent) to a HSN and the security/privacy of their health-related data has validity.

Users of a HSN may be unaware at time of registration of the secondary uses and disclosures of their health-related data to third parties, unless they read the T&Cs and PP statements. Users cannot assess the risks of divulging PHI unless they know the organisations to which their information may be disclosed and how their information may be used. A HSN may allow third party websites and applications to automatically have access to users' health information. This could be for the purpose of targeted advertising or through synchronicity with other websites to create a comprehensive digital profile of that person's private data, unbeknown to the HSN user[14]. Additionally, cookies can be used on websites to track users and deliver targeted advertising. Cookies can also be used to authenticate users for multistep web transactions or automatically terminate a login session[15]. Many websites use cookies, and the PatientsLikeMe site is no exception. However, cookies were not designed with the protection of security and privacy of data in mind[15]. Thus, the PatientsLikeMe HSN suffers from the same problems as other websites, using cookies, as the security and privacy of their members' health information cannot be truly guaranteed.

In this paper, we seek to deepen our understanding of the issues surrounding eConsent on a HSN site – PatientsLikeMe - by taking a qualitative approach. The aim of this research is to improve both the form and accessibility of contractual information presented to HSN users, by exploring the challenges and risks of sharing PHI on a HSN. The remainder of this paper is structured as follows: methodological use of the grounded approach to interpret focus group data, with a conceptual model and illustrative examples from research participants presented within the findings. This is followed by a discussion on the main themes that emerged from the research and the implications for the future presentation of T&C and PP on HSN platforms. Future phases of this research aims to explore the creation of simpler and clearer T&C and PP when users provide eConsent on HSN sites.

2. Method

This ongoing research funded by the Wellcome Trust is in the initial phases of a 12-month project. Ethical approval for this research was granted by University College Cork Ethics Committee. In February 2017, we conducted a two-step process to the research design of this stage of data collection. Step 1 required participants to register on a HSN (i.e. PatientsLikeMe) using a mock profile, participants were observed at this stage. Direct observation can provide rich qualitative accounts of device usage and human behavior[16]. While we are aware that participant behaviours may change due to observational reasons[16], it is important that observation is done to ensure that this stage is completed. Step 2 collectively involved participants in three focus groups, that ran for ninety minutes each, to provide a rich understanding of the eConsent process, allowing the researchers to answer 'How' and 'Why' questions in relation to this study. Questions revolved around six topics – their experience of giving eConsent on this HSN, concerns they may have about T&C's and PP statements on this site, any security or privacy issues highlighted, their anticipated registration behaviours in the future, and what changes they would like to see to registration process – in terms of eConsent and the presentation of T&C and PP information. A convenience sample of 24 graduate business students were enlisted to this study, aged between 25 and 34 years, with 6:18 Female to Male ratio.

3. Findings

We present findings from this qualitative approach by looking at the concepts that emerged from the data collection and by using illustrative examples of user's views obtained from the focus groups. Through observation of registration practice, it was found that no participants opened the T&C's and PP at time of registration onto this HSN. The dimensions that characterise the experience of the registration on a HSN are conceptualised as the following (see Fig.1):

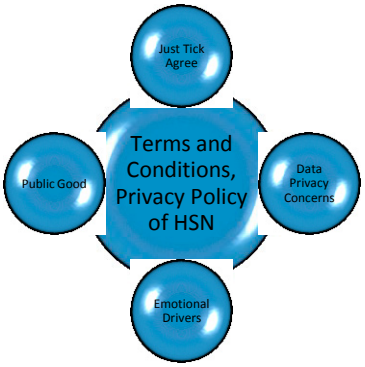


Fig. 1. User dilemmas on eConsent following registration on this HSN.

1. Just Tick Agree - can be characterized as the process whereby user's registering onto a HSN involves scanning through the registration process, involving very slight or minimal attention to the T&C's and PP statements, to enable users to join. There are two elements to this process, 1) the behavioural and 2) the motivational. In terms of the

behavioural element it was apparent from focus group discussions that multiple participants would just *"click and go"* (see Table 1 for participant ids). This was considered as a usual behaviour, based on past learnt experience of what was expected of them as users. Prior experience of *"nothing bad happening"* (F3.M4) reinforced these behaviours, or an automatic process involving impulses. The motivation for Just Tick Agree actions, were mostly based on not having the interest or time to read the T&C's and PP statements. Many stating this was a habitual behaviour based either on laziness, not wishing to spend time reading these documents, or impatience, wanting *"instant gratification"* (F3.M5) or no attention given to the reflection of evaluations or plans. Additionally, users knew that if the motivation to join the HSN was high enough, then the implications of these documents were secondary, as they were *"going to agree regardless"* (F1.M1). Table 1 provides some additional quotes to support the 'Just Tick Agree' mentality of the focus group participants.

Table 1. Conceptual Category – Just Tick Agree and Participant Statements

Participant ID	Statements
F1.F1	"Can't be bothered, just click"
F1.M1	"Didn't think about it, just ticked T&C, as usually do"
F3.M5	"I always just tick that and never look at it"
F2.M4	"I just ticked the box and away I went"

2. Public Good - The belief that the sharing of PHI with others could be used to promote public health emerged from the data, indicating a benefit for the Public Good. This idea applies to the registration on a HSN, as the use of aggregated data would mean that patterns of behaviours could be researched to potentially yield positive results in the development of medical advancements. The benefits of using this HSN site was recognised by participants and was a factor they would consider when deciding to join a HSN website such as this. The usefulness of joining, sharing and learning about health issues on a patient-to-patient site was evident in statements made by quite a few of the participants. This form of reciprocal altruism was expressed by a small selection of participants within each focus group – *"I don't have a problem giving away my most personal information when signing up to a HSN… give as much as possible to help me make the most of the HSN and get the most benefit"* (F1.M1). Further comments on this concept are represented in Table 2.

Table 2. Conceptual Category – for the Public Good and Participant Statements

Participant ID	Statements
F2.M4	"For the good of the people in the country"
F1.M1	"Anyone sharing are going to get more of a positive than a negative"
F1.F1	"So if the information is used for the positive"

3. Data Privacy Concerns found in this study revolved around three issues; namely, (1) Confidentiality of their PHI, (2) the Security of PHI on this HSN and, (3) Third party access to their PHI (as represented in Table 3). First, confidentiality in PHI has always been governed in the healthcare arena by legislation e.g. the Data Protection Act (DPA, Ireland, 1988 – Amended 2003) or the Health Insurance Portability and Accountability Act (HIPPA, USA, 1996). The confidentiality of users of online health-related data are not so comprehensively governed by these Acts. Most participants recognised the limitations of this HSN to keep their health-related data private – *"there is no way to guarantee the confidentiality of these things"* (F2.M2). The T&C's and PP statements offer some reassurances over the accessibility of patient data on this HSN but *"what about the future?"* (F2.M2). One of the points made in the T&C's and PP statements was that the HSN retained the right to sell on data at any time and without permission or consent of users, as well as retaining the right to change the T&C's and PP statements at any time. Not only did this not give reassurance to users about the confidentiality of their health data on this HSN, it also raised questions about the future implications of sharing their health data.

Second, security and privacy of health information online was a hot topic for these focus groups. Concerns were aired about the use of Cookies on this HSN – *"I won't share personal information on a health website using my own personal details, because I don't want them traced back to me"* (F2.F1). Additionally, there was concern over the ability of these web design components to not only track and trace users behaviours, but to use this information as a predictor of future behaviours – *"Predicting my future behaviour or health, that's wrong"* (F2.M5). Another participant questioned whether privacy truly exists expressing that it may be the case that in the future *"life will be a public issue"* (F2.M2).

Thirdly, third parties accessing a user's HSN data was clearly disconcerting for focus group participants. There was on consensus with people being unhappy about third parties getting access to their health-related data and concerns about how data was going to be used – by insurance companies, employers and pharmaceutical companies. However, if users of this HSN could see the beneficial aspects to third parties having access to data e.g. reducing the price of drugs, identifying the need for the development of new medicines and helping to solve common health problems, then sharing health data with these parties would become less of an issue. Yet, the current practice of not clearly explaining the role of third parties on this HSN led participants to conclude that *"there was no such thing as a good third party"* (F3.M2) and that "*third parties were the ones getting all the advantages"* (F3.F1). Table 3 provides evidence from focus group participants to further corroborate the findings presented in this section.

Table 3. Conceptual Category – Data Privacy Issues and Participants Statements

Participant ID	Statements
F2.M2	"There is no assurance that confidentiality is respected"
	"If this information… is being used for a purpose… that it was not intended… who is accountable for the consequences?"
F3.M4	"Health Insurance might go up"
F1.F1	"Employers might discriminate against you"

4. Emotional Drivers – some of the emotions expressed about the experience of joining a HSN site, following discovery of the contents of the T&C's and PP statements, were – fear, suspicion, distrust, annoyance and anger about their lack of control over their PHI (see Table 4 for supporting evidence). The interesting thing about these emotional drivers for action, is that it was only when participants retrospectively evaluated the impact these T&C's and PP's could have in terms of their PHI on this HSN, that these negative emotions were expressed. Without taking the time to actually read these documents, participants were unaware of the implications for their data, and how they truly felt about these issues. In terms of reading these documents, although there is a predominately learnt behaviour of quickly scanning or skipping this part of the registration process, on further reflection of this registration process and T&C/PPs comments upholding mistrust included – *"that they have cleverly hidden them for a reason"* (F3.F1) and that *"you would want to be a lawyer to understand them"* (F3.M1).

Table 4. Conceptual Category – Emotional Drivers for action and Participant Statements

Participant ID	Statements
F1.M4	"Fear of what would happen to my data"
F1.F1	"This health information on me being sold…I'd be very scared about that"
F3.M3	"I'd be annoyed … if it based anything on me" and
	"I am just not that happy with it"

4. Discussion

The focus groups have revealed that there is much distrust, concern and suspicion surrounding the T&C's and PP currently adopted by this HSN site. Firstly, the *'Just Tick Agree'* behaviour of users is concerning, as users automatically consented to the use of their PHI without reading or fully been aware of T&C's and PP requirements. This corroborates the work of Custers et al[17] who found that a clear majority of their survey respondents (n=8621) on the topic of informed consent in social media use failed to read T&C's and PP requirements and automatically proceeded with little awareness of what the T&C's and PP contained. The registration process involved participants using mock profiles to register on the HSN created a remoteness or distance for the actual participant; no personal details were input into this HSN site. It could be that the '*Just Tick Agree'* behaviours that were enacted at time of registration could have been influenced by this factor, and if participants' PHI had been required, a more careful attitude may have been adopted. Yet, using a mock profile could also be viewed as a limitation of this study.

Secondly, perceived societal benefits for the public (i.e. For the *Public Good*) were identified from the data. This finding corroborates the work of Aitken et al[18]. The results presented in their paper indicate widespread (conditional) public support for data sharing and linkage for research purposes and subsequent societal benefits for the public good, however, a range of concerns exist. Identifying clearly how and why data will be secondarily used by HSNs/third parties and the advantages, disadvantages and achievable outcomes associated with use of registered users' data in T&C's and PP statements could ultimately increase user registrations to sites. The lack of details surrounding the secondary use of data in T&C's and PP statements is considered a barrier for people consenting to and contributing on HSNs.

Thirdly, *Data Privacy Concerns* reinforce prior research into this subject[5] whereby HSN users expressed concerns about the electronic collection and storage of their health-related data. It is not uncommon to read reports of cases where the security of health information has been breached i.e. an article on Google gaining five-year access to the health data of 1.6 million people[13]. While HSN users often share their data privacy concerns, few individuals actually perform the initial actions (i.e. reading T&C's and PP statements) for understanding how and why their PHI on HSNs will be actually used. This could be the result of the instant and readily available information people have nowadays through their technological devices. Reading T&C's and PP statements could be considered a time-consuming activity and some people (perhaps more especially the 'generation z' population) may well have little patience for conducting this vital activity.

Finally, the findings reveal several *emotional drivers* for individuals when participating in this research, which were predominantly negative in nature. These negative emotional drivers could be reversed when designing the access and readability of T&C's and PP's used by this HSN, to promote positive feelings. Building on the work of Michie, van Stralen and West[19], this could be achieved by introducing several measures for behavioural change e.g. the education of HSN users at time of registration by (1) simplifying the T&C's and PP statements, thus increasing user knowledge, awareness and understanding of the implications of joining; (2) providing a model on this HSN website that illustrates role model behaviours to inspire behavioural change and, (3) enabling user choice at time of registration by increasing the means for choice, whilst reducing the barriers for choice, over the control of their health-related data.

So, what could be done to improve the presentation of T&C's and PP's on this HSN site? Simplification of language on these documents would assist in educating users on the T&C's and PP's for this HSN. Perhaps using a model of how users should register onto this HSN would inspire behavioural change and encourage a more questioning attitude when ticking check boxes. Furthermore, offering differing levels of data control at time of registration, providing options to opt in to the level of data sharing that serves user needs could improve their trust relationship with the HSN. Ultimately, to offer users control to explicitly influence the level of granularity of data and the type of data made available to their network and to third parties.

These suggestions to return control over PHI data back to the HSN user, are in line with the proposed changes to be introduced in 2018 by the General Data Protection Regulation to be enforced on 25 May. Essentially this regulation will give citizens more control over their personal data and is also aimed at unifying regulations on Data Protection within the EU[20]. What this will mean for the HSN user, is that potentially, the eConsent process (including T&C's and PP's) maybe presented in a more clear-cut manner in the future.

5. Concluding remarks

Few would question the potential value a HSN offers users in terms of sharing their experiences and learning from each other[1]. It may increase understanding of drug usage and side-effects, the controllability of symptoms and feedback on various treatments for a variety of conditions. However, as highlighted within this research, such positivity for the greater good comes with user concerns – worries about health data usage, data accessibility, data traceability and the potential for this data to be used to predict future behaviours or conditions. Users of HSNs, not only want to have T&C's and PP's more clearly explained at the beginning of the registration process, but also want more control over the privacy levels of their PHI, as stated in feedback – "*there is nothing as private and sensitive to you as your health data*" (F2.M3). This study is not without its limitations; the sample was specific to the context in which it was drawn. Yet, this was an accepted limitation of this qualitative research study. These results are descriptive and representative only of this sample set. Moving forward with the research such limitations would need to be addressed. Future research should look at alternative formats for the presentation of T&C's and PP's to users on HSN sites, to obtain user feedback on these. The findings presented in this paper form a subset of a larger project. The design of the next stage of our project will focus on the visual representation of T&C's and PP statements from a user experience perspective. It is hoped that we will better address the education, modelling and enablement aspects of user involvement when registering onto a HSN.

Acknowledgement

We would like to acknowledge the Wellcome Trust Grant for funding the CHASM Project Seed Award 201607/Z/16/Z.

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