

Ethical Risks Inhabited in Social Networking Sites: A Case Study on PatientslikeMe.com

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Abstract. This article aims to address the potential risks of standard contract used by the emerging social networking sites. PatientslikeMe.com is a medical community website which provides members a platform for sharing health or medical treatment information. It's business model bases on selling members' medical records or figures without their identifications to pharmaceutical companies or research institutions. In May 2010, someone registered in PatientslikeMe with a pseudonym and used a computer program to collect other members' private information posted on the website forum. In fact, there are no clear legal rules and regulations to avoid such a problem in the cyberspace. Thus, this article uses a framework of information ethics to analyze this case and to discuss possible issues in four parts: information privacy, information accuracy, information property, and information accessibility.

Keyword: Social Networking Sites, PatientslikeMe.com, Information Ethics, Computer Ethics, Information Privacy, Information Accuracy, Information Property, Information Access

1. Introduction

The aim of this study is to discuss the risk of unnoticed abuse in the computer. The standard contract of PatientslikeMe.com is used as an exemplar for analysis. This study uses the framework of information ethics to analyze the case and to clarify relevant issues, including information privacy, information accuracy, information property, and information accessibility.

From the perspective of information privacy, this article discusses whether the PatientslikeMe.com has authority to disclose its members' healthy information to non-members, the pharmaceutical company can acquire the members' information, and a third party can invade other users' privacy by means of data-mining technology. From the perspective of information accuracy, this article discusses who should respond for the accuracy of users' information on PatientslikeMe.com and whether it is proper to advertise the commercial messages by a disguised member of the website. In the information property part, this article analyzes who owns the data on PatientslikeMe.com, who owns the data when PatientslikeMe.com is assigned to or merged by another, and who owns the data remained on the system when a member chooses to deactivate his/her account. Finally, in the information access part, this article discusses who is allowed to access the data on PatientslikeMe.com and whether the membership eligibility stipulated in the standard contract could fully govern the access to PatientslikeMe.com.

The result of this article discovers that the website, which lacks of valid authentication mechanism, may lead to the issues of information privacy, information accuracy, and information access. This article suggests that the website may add more patient groups and thus the number of members in each group can be reduced.

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By this way, the members in the same group may be more acquainted with each other, so as to solve the online anonymity problem. Furthermore, this article finds that the information ownership of many online users is intruded because only few sites provide their users the informed consent or the autonomy to control their own data. In conclusion, this article urges that the authorities should adopt OECD's Guidelines on the Protection of Privacy and Transborder Flows of Personal Data to enact domestic Personal Data Protection Law, and encourages all website operators to adopt those principles when drafting the term of use or the standard contract.

1.1. PatientslikeMe.com: a brief introduction

PatientslikeMe.com is a social networking site that members can discuss or share health information on it. The website is founded in 2004, and its function is similar to Facebook. Members of PatientslikeMe.com not only can share their feelings, but also exchange treatment and symptom information.

PatientslikeMe.com was evaluated by Business Magazine in 2007 to be one of the 15 companies. The company has a special business model: it sells users' data without personal identification to pharmaceutical and medical companies.

It could be possible that members often neglect that their personal data are quickly collected by the site and disseminated to others when they make use of rich information on the site. However, a dispute occurred in May 2010, a new member used a sophisticated software to collect every single message on PatientslikeMe.com's private online forums.

1.2. The notion of information ethics theory: computer ethics and ethical framework

Moor (1985) thought that most people may know a lot about inputs and outputs of a computer. But they are not aware of internal processing of a computer. So the invisibility is an important fact about computer ethics. The invisibility factors include invisible abuse, invisible programming values, and invisible complex calculation. For instance, the dispute happened on PatientslikeMe.com is a classic case of invisible abuse. The invisible abuse is the intentional use of the invisible operations of a computer to engage in unethical conduct. For example: surveillance, collect, copy, tamper data and so on. The unethical activity is against personal right of privacy.

When various technologies develop in information age, there exist two major problems should be concerned regarding unethical activity: (1) the policy vacuum and (2) the standard contract.

Mason's (1986) PAPA model provides a good guideline to examine the PatientslikeMe.com case. There are four concepts in Mason's framework: information privacy, information accuracy, information property, and information access. These four issues are needed to be discussed in this case.

Information Ethics: Privacy

What information about one's self or one's associations must a person reveal to others? Under what conditions? What things can people keep in themselves and do not have to be forced to reveal to others? Whether the website is able to disclose members' health information to non-members? Whether the pharmaceutical company can oversee the members' information? Whether the person may invade the users' privacy by means of the data-mining technology?

Information Ethics: Accuracy

Who is responsible for the authenticity, fidelity and accuracy of information? Who is responsible for the accuracy of users' information on PatientslikeMe.com? Whether it is proper to pass the commercial messages by someone who disguises as a PatientslikeMe.com's member?

Information Ethics: Property

Who owns information? Who owns the data on PatientslikeMe.com? Who owns the data when PatientslikeMe.com is assigned to or merged by another? Who owns the data remained on the system when a member chooses to deactivate his/her account?

Information Ethics: Access

What information does a person or an organization have the right or the privilege to obtain, under what

conditions and with what safeguards? Who is allowed to access the data on PatientslikeMe.com? Whether the membership eligibility indicated in the standard contract could fully govern the access to PatientslikeMe.com?

2. Discussion and Suggestions

All these questions need to be answered, although this article doesn't have all the answer yet. But there are two things can be done in this case to avoid ethical problems.

The website lacks of authentication mechanism that may lead to the issues of information privacy, information accuracy, and information access. A new mechanism that integrates features of Social Networking Sites' to avoid misuse and deception of personal identity is suggested. For example, the number of members in each group can be reduced, or the members in the same group may enhance the acquaintance with each other.

The other is providing users a informed consent or the autonomy to control their own data (Individual Participation). Users have rights of managing their own information property. If website's manager rejects users' right to manage their personal data, who should to explain in reason. So users have rights to delete and alter their own data.

In addition, U.S. Government, including the Whitehouse and the General Accounting Office, has commenced design of a nationwide, interoperable platform for electronic health information which is slated for completion in 2014 from the PatientslikeMe.com case, we have already seem so many potential problems needed to be addressed. Therefore more guidelines and regulation should be raised. For example, OECD' s Guidelines on the Protection of Privacy and Transborder Flows of Personal Data (1980). So this study suggests the government should adopt OECD' S Guidelines and encourage all website operators to adopt those principles.

There are eight parts in OECD principles They are collection limitation, data quality, purpose specification, use limitation, security safeguards, openness, individual participation, accountability. This study provides a comparison of OECD principles and ethical framework (table 1).

With the development of social networking sites and the case of PatientslikeMe.com has demonstrated three principles of information ethical framework are extremely important. The first is collection limitation: when the websites collect user's information they have to well inform the users. The second is security safeguards. Because the health information is very private, websites have to offer safeguards to avoid private information be leaked. The third is individual participation. Users should have rights to choose who can use their own data. In sum, we should take more concern on these issues.

3. References

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APPENDIX

Table 1. Comparison of OECD Principles and Ethical Framework

Protection of Privacy and Transborder Flows of Personal Data	Ethical framework
Collection Limitation	Privacy
Data Quality	Accuracy
Purpose Specification	Privacy, property
Use Limitation	Privacy
Security Safeguards	privacy, Access
Openness	Privacy
Individual Participation	Privacy, Property
Accountability	privacy, Access, property, Access