

Ethical Issues of Social Media Usage in Healthcare

K. Denecke¹, P. Bamidis², C. Bond³, E. Gabarron⁴, M. Househ⁵, A. Y.S. Lau⁶, M. A. Mayer⁷, M. Merolli⁸, M. Hansen⁹

¹ University of Leipzig, Innovation Center Computer Assisted Surgery, Leipzig, Germany

² Aristotle University of Thessaloniki, Faculty of Health Sciences, Thessaloniki, Greece

³ Bournemouth University, School of Health and Social Care, Bournemouth, United Kingdom

⁴ The Arctic University of Norway, Faculty of Health Sciences, Tromsø, Norway

⁵ College of Public Health and Health Informatics, King Saud Bin Abdulaziz University for Health Sciences, Ministry of National Guard - Health Affairs, Riyadh, Kingdom of Saudi Arabia

⁶ Centre for Health Informatics, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

⁷ Department of Experimental and Health Sciences, Universitat Pompeu Fabra - IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

⁸ University of Melbourne, Health and Biomedical Informatics Centre, Melbourne, Australia

⁹ University of San Francisco, School of Nursing and Health Professions, San Francisco, USA

Summary

Objective: Social media, web and mobile technologies are increasingly used in healthcare and directly support patient-centered care. Patients benefit from disease self-management tools, contact to others, and closer monitoring. Researchers study drug efficiency, or recruit patients for clinical studies via these technologies. However, low communication barriers in social-media, limited privacy and security issues lead to problems from an ethical perspective. This paper summarizes the ethical issues to be considered when social media is exploited in healthcare contexts. **Methods:** Starting from our experiences in social-media research, we collected ethical issues for selected social-media use cases in the context of patient-centered care. Results were enriched by collecting and analyzing relevant literature and were discussed and interpreted by members of the IMIA Social Media Working Group. **Results:** Most relevant issues in social-media applications are confidence and privacy that need to be carefully preserved. The patient-physician relationship can suffer from the new information gain on both sides since private information of both healthcare provider and consumer may be accessible through the Internet. Physicians need to ensure they keep the borders between private and professional intact. Beyond, preserving patient anonymity when citing Internet content is crucial for research studies. **Conclusion:** Exploiting medical social-media in healthcare applications requires a careful reflection of roles and responsibilities. Availability of data and information can be useful in many settings, but the abuse of data needs to be prevented. Preserving privacy and confidentiality of online users is a main issue, as well as providing means for patients or Internet users to express concerns on data usage.

Keywords

Social media, health care ethics, information science, patient-centered care

Yearb Med Inform 2015;10:137-47

<http://dx.doi.org/10.15265/IY-2015-001>

Published online August 13, 2015

1 Introduction

Due to improved possibilities and means to obtain information about diseases and treatments that go hand-in-hand with the development of social media and Internet technologies, patients are becoming more informed [1], and they increasingly want to be engaged in their care [2]. Social media are digital media and technologies that enable users to exchange information and to create media content individually or in community with others. This media is increasingly becoming a tool supporting healthcare processes, gathering and sharing information, bringing people together, and encouraging social networking and communication regarding health topics [3], and it supports in this way patient empowerment, i.e. it brings patients into the position to take control of their healthcare needs. The evolution of the Internet from a limited, technical resource, to today's dynamic "Web 2.0" where people are able to share information means increasing numbers of people living with a long-term condition are now putting personal health information into the public domain, including discussion boards, social network sites, blogs, videos and virtual environments [4].

1.1 Patient-centered Care and Medical Social Media

The phenomenon of social media and its increased importance in the private as well

as in the public sector show there are many potentials even in healthcare settings enabling patient-centered care. In particular, individuals suffering from chronic diseases are using social media more and more to communicate with others, exchange information, and human experiences. **Peer-to-Peer healthcare** is emerging as a source for patient information and support [5]. Patients, family members, and friends share personal medical information, receive emotional support, or request guidance and advice from healthcare professionals via social-media sites. **Social networking communities and data sharing platforms** support sharing experiences with conditions, symptoms, and treatment outcomes, but also enable to track personal health and be actively involved in one's own care coordination. For researchers, such data provide new opportunities to analyze observational data to confirm results from randomized trials [6]. Increasingly, social networks are being used to investigate adolescent and young adult behaviors and personality traits [7], as well as for data collection and education purposes. One application area in this context is **the recruitment of patients for clinical trials** based on social-media profiles or the exploitation of social-media data for epidemiological studies [8]. Beyond, physicians may use social networking to **crowdsource answers** to individual clinical questions. Researchers have found, based on the data posted on Twitter, they can **detect and monitor disease activity**, most notably disease outbreaks such as cholera

and influenza [9, 10], but more recently, data about issues like headache appearance was collected from tweets [11].

These examples show patient-centered healthcare, social media, and the Internet are beginning to come together. Patient behavior has notably changed already and will increasingly influence healthcare delivery and research. A couple of ethical questions arise when it comes to the use of social media in healthcare settings. If you have a Facebook or MySpace page with 600 “friends” is that your private page, or a public document? What do researchers need to consider when developing monitoring applications for healthcare using social media? What do health providers have to consider with respect to ethical questions of social-media usage?

1.2 Ethics in Healthcare

Ethics is defined as the discipline dealing with what is good and bad and with moral duty and obligation [12]. *Public health ethics* deal with the specific moral questions regarding public actions for disease prevention, life elongation, or psychological and physical well-being. This is in contrast to *medical ethics* which concentrates on the relationship between patients and doctors. The issue of how ethical principles may be applied to online health research is a current challenge for researchers, but also for health professionals and patients alike. In this paper, we start to explore these questions and topics.

2 Objective and Methods

The objective of this work is to examine the ethical implications of the aforementioned trends in the state of the art and to provide topics to be further addressed in the future. For this purpose, we selected use cases from our research work and analysis about the use of different social media platforms for health purposes. They include:

- the use of social media for the youth and the elderly,
- the impact on the patient-doctor

communication and relationship,

- crowdsourcing in healthcare,
- the integration of social media in clinical environments,
- the use of wearable technologies, and
- research regarding medical social-media including harnessing patient-reported data, conducting online surveys and participant recruitment.

We collected and summarized ethical issues related to these use cases from our experiences and conducted a review of the literature (both white and grey). Further, we performed an environmental scan of popular and current applications and services in this area. The results were then discussed and interpreted. We concentrated on identifying and discussing relevant ethical aspects without writing a systematic review to match with the IMIA Yearbook objectives and structures. The authors of this work, all members of the IMIA Social Media Working Group (<http://www.imia-medinfo.org/new2/node/289>), have skills and expertise to discuss around the results since we have a deep interest and a professional experience of using social media in healthcare. We have experienced ethical issues in our work.

3 Ethical Issues of Social Media Usage

3.1 Use of Social Media for Youth

There is a group of people who have grown up with the Internet: the youth, or the digital natives, regularly engage with new social-media [13], base their personal identities online [14], and social media is their natural environment. *Youth* is defined as a transition period from the dependence of childhood to adulthood’s independence [15]. It is also the period when one’s personal identity is formed, based on both individualities and the social environment [14]. For this digital native generation, the online social-media represents a space for connection, identity exploration, a space to express ideas, sexual identities, feelings, problems, and also a space where we receive feedback from others [16].

For a majority of youth, online social networking sites are their first point of call when they want to find information, including health-related matters [17, 18]. Thus, social media is a rich environment to recruit youth participants to participate in research. For example, recruiting participants from Facebook and Twitter is one of the most effective recruitment strategies in youth-related research studies [19, 20].

Although using social media to recruit participants for research is positively viewed by the youth [21], it presents a number of ethical issues that need to be addressed. Obtaining informed consent from adolescents via social media represents a number of concerns [19]. Recruited participants over 18 years may provide their consent online, or their written consent, if they are redirected to a study site. But, how may we obtain parental consent from those contacted or interested under 18 years of age via social media [19]? In fact, is it ethical for study advertising material to be circulated in social media, targeting at those who are under-aged, and may have not reached the cognitive maturity to decide whether to participate or not? An alternative (and arguably more ethical) way to recruit very young people would be to target parents rather than children [19]. However, one needs to remember that policy settings in social media frequently change. For example, although Facebook reviews all the advertisements targeting young people under 18 years, their privacy policies can change without prior notice, and there is no mechanism to confirm one’s age declared online.

When trying to reach youth through social media, whether it is for public health education or for public health monitoring, the same confidentiality and privacy rules that are applicable offline should also apply [22]. Although social media is a platform that allows a researcher to easily reach their targeted audience, establishing a dialog with them may not be as easy as one perceives. A recent qualitative study examining teenage patients’ privacy concerns related to health matters revealed most participants did not disclose their personal health information on social media [17]. In this study, Facebook was seen to be a place for these teenage patients to be ‘regular’ teenagers, to stay

up-to-date about their social life, and not seen as a place to discuss their diagnosis and treatment. In fact, the majority of them did not use social media to come into contact with others with similar conditions. Using social media as a health intervention needs to delicately consider participants' concerns for privacy. Some young users may prefer to interact with others anonymously, perhaps because they are struggling with sensitive issues, such as their sexual identities, or chronic diseases [17, 23]. Some would not want others to find out their true underlying health status and concerns, or they would not want updates about their health to be 'broadcasted' to their social network. On another scale, there are those who readily share very personal information that may be accessible by the broad general public [16]. In any case, young individuals' privacy and their level of comfort in discretion of health matters must be respected and preserved in the social media setting.