

# Ethical Aspects of Using Medical Social Media in Healthcare Applications

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**Abstract.** The advances in internet and mobile technologies and their increased use in healthcare led to the development of a new research field: health web science. Many research questions are addressed in that field, starting from analysing social-media data, to recruiting participants for clinical studies and monitoring the public health status. The information provided through this channel is unique in a sense that there is no other written source of experiences from patients and health carers. The increased usage and analysis of health web data poses questions on privacy, and ethics. Through a literature review, the current awareness on ethical issues in the context of public health monitoring and research using medical social media data is determined. Further, considerations on the topic were collected from members of the IMIA Social Media Working group.

**Keywords.** Social Media, Ethics, Information Systems

## 1. Introduction

The advances in internet and mobile technologies changed the way how people access, use and share information. Social-media tools came up and now provide technology tools to bring people together and encourage social networking and communication [1]. Data and experiences are exchanged via social media tools such as instant messaging, blogs, social networking (e.g. Facebook) or video sharing (e.g. YouTube).

Even in the medical domain, an increased usage has already begun. New ways of communicating were opened and enabled for timeless and location-independent information exchange. 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 that increasing numbers of people living with a long-term condition are now putting personal health information into the public domain, including discussion boards [2]. At the same time, individuals (patients) start to be better informed since information is available and accessible very easily in the Web [3]. Patient empowerment becomes reality through the availability of information in the Web: Information on diseases and treatments is easily accessible, can be consumed by everyone and discussed with others.

For researchers, the availability of social media data and tools provides new opportunities addressed in the research field health web science. Health web science is the medico-socio-technical science that investigates how the World Wide Web evolves

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with respect to health issues, how health related data provided through the Web can be processed and how tools that make use of web technology can be used in healthcare. In other words, health web science is about patients, doctors and health carers, the information they are providing, the tools they can use to communicate and about methods to support in analysing the provided information. Among others, health web science researchers (1) utilise the internet to collect data, (2) study how healthcarers and patients use and access the internet, (3) employ visual and textual analysis, semiotic analysis, and other methods to study health-related content in the Web.

One application area in this context is the recruitment of patients for clinical trials based on their social-media profiles or exploitation of social-media data for epidemiological studies [11]. Beyond, the communication barrier for sharing messages on one's own health status is much lower in the web. From such statements, potential health risks can be identified and a population's health status can be monitored [6]. Social media can capture emerging disease trends before official data is available [12]. Web monitoring comprises the surveillance of social media during outbreaks or continuously to identify public health concerns. The term "infodemiology" was introduced for this field [13].

Appreciation of the positive side of social media is balanced by their potential for negative developments, such as disseminating rumours, undermining authority and promoting terrorist acts [4]. Increasingly, social networks are being used for research to investigate adolescent and young adult behaviours and personality [5] or for participant recruitment purposes as well as data collection purposes.

As researchers who use medical social media for public health monitoring [6], we have occasionally heard concerns raised by human subjects committees and other researchers regarding privacy issues in conducting research in this setting as well as on related obligations. Given these privacy concerns, questions about the appropriateness of researchers' use of medical social media to collect information or contact participants or to monitor the health status requires attention. 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 and what do health officials have to consider with respect to ethical questions? Is there an awareness of the ethical questions related to social media usage for health monitoring research? In this paper, we start collecting answers to those questions.

Ethics is defined as the discipline dealing with what is good and bad and with moral duty and obligation [24]. Public health ethics deals with the specific moral questions of public actions for disease prevention, life elongation, or psychological and physical well-being. This is in contrast to medical ethics that concentrate on the relationship between patients and doctors. The issue of how ethical principles can be applied to online health research has provided a challenge to researchers. Ethical and legal concerns regarding collection of data from social networks have been explored in a handful of articles and legal cases [7-9]. In this paper, the ethics of social media usage in health web science and in particular in health monitoring is examined.

The initial idea was to perform a questionnaire on the topic collecting to identify ethical issues that are relevant and need to be addressed when it comes to making use of medical social media resources in healthcare. We wanted to create a questionnaire for its distribution among healthcare professionals and health officials on the one hand and computer scientists on the other hand to identify the perception of the various user groups towards ethical aspects. It turned out that specification of relevant questions is

difficult. Thus, we decided to perform a literature review and ask researchers working in health web science on their perceptions of ethical issues. Results are presented in this paper. Technically, it is possible to analyse social media data from the web. A broad range of methods is necessary to realise monitoring and analysis of social-media data. Our interest in this work is to identify the ethical issues that are of relevance in this context of health monitoring using social media.

## 2. Methods

In order to collect information of ethical issues to be considered within public health monitoring and internet research, and to summarise the current awareness of the research community with respect to ethical issues, we performed a literature review and collected input from researchers working in health web science. Details about the methods are described in the following.

### 2.1. Literature review

A literature review was performed to collect research publications on ethical issues in the context of health web science and to identify relevant ethical concerns. For this purpose, a PubMed search was run with the search terms: "ethic" and "social media". The result set was restricted to entries with free full text available and a publication data in the last 10 years. In a manual assessment the results were filtered relevant or irrelevant. Publications were included into the review when: (1) dealing with ethical aspects of social media usage, and (2) concentrating on social media for clinical research and healthcare. Publications were excluded when they are:

- not at all dealing with social media for clinical research and healthcare,
- general discussions or commentaries of social media usage in healthcare by health professionals / clinical adoption of social media,
- dealing with social media for healthcare education, or health promotion (in contrast to healthcare, clinical research and monitoring).

The search resulted in 91 results. After initial scanning using the inclusion and exclusion criteria, twenty publications were selected as relevant, from which again 14 were filtered out after reading. Only six publications are relevant for our review. The majority of the papers was published since 2011. We collected from the resulting papers the mentioned ethical aspects.

### 2.2. Collecting feedback from IMIA Working Group Members

Given the fact that literature on ethical issues of health web science is still only available to a very limited extent, we collected input from the IMIA Social Media Working Group (IMIA SMWG, <http://www.imia-medinfo.org/new2/node/289> (accessed:13.12.2013)). That working group aims to be IMIA's vehicle for stakeholder engagement in social media and targets at identifying, exploring, collaborating, and disseminating research on the use of social media for healthcare. Its members comprise representatives of the international health informatics community. Within the group, applications of social media are explored with particular applications to: 1) health care delivery, 2) health care professional education; 3) public health; 4) clinical and disaster

medicine; and 5) research.

Through the IMIA SMWG mailing list, we asked the 45 registered members for input related to the following questions: What do you think about the following issues when it comes to use of social media for public health monitoring?

- Is privacy of individuals violated when social media data is exploited a) by health organisations for public health monitoring, b) by researcher ?
- What are the responsibilities of health organisations when health problems are detected through social media monitoring: a) identifying the individuals b) preparing actions without any concrete knowledge?
- What is the interpretative value of the results collected from social media monitoring? To what extent should health officials rely upon them? How to use them appropriately?

Three research groups replied to these questions.

### 3. Results

#### 3.1. Summary of literature review

The six publications that were selected as relevant in the literature review cover ethical aspects of two different use cases of social media: social media research and social media in the patient-doctor-relationship. None of the papers was explicitly referring to ethical issues of public health monitoring. In the following, we summarise the ethical issues mentioned for these two use cases.

*Ethical issues in social media research.* There were two studies included in the result set that collected and analysed the views of social media users regarding (unintended) participation in internet research. Moreno et al. [14] report a study to explore participants reactions to direct experience with Facebook research methods. The purpose of this study was to determine older adolescents responses after learning that they were participants in a research study that involved identification of participants using Facebook. User views on privacy issues related to conducting research with online social network data of users were collected. The authors report that the majority of the participants viewed the use of Facebook in a research study positively.

One reason for participant's positive attitude may be that they do not perceive personal risks to disclosing large amounts of information. To address the concerns of persons with negative attitude towards their participation, it is suggested to promote a greater understanding of information sharing in a research setting [14].

Bond et al. [15] described an ethics case study of using Facebook to deliver a sexual education program to youth and young adults, with a focus on a description of potential ethical risks related to beneficence, information and comprehension, equity and special populations, and confidentiality and security. They explored the views of contributors to online diabetes discussion boards with regards to if (and how) they feel their contributions to boards should be used by health researchers [15]. To study this question, they performed an email interview. The participants agreed that forum posts are in the public domain and that aggregated information could be freely used by researchers. Using aggregated data is acceptable to the community that created it. Using quotations ranges from being totally acceptable to totally unacceptable.

Bond et al. summarised the ethical issues that researchers should consider: Researchers should (a) consider whether an online social networking site is an appropriate place to implement a research study; (b) offer opportunities to review informed consent documents at multiple times and in multiple locations throughout the study; and (c) collect data outside the social networking site and store it behind secure firewalls to ensure it will not be accessible to any person on the social networking site. Conducting research on social media sites requires deliberate attention to consent, confidentiality, and security.

*Applications of social media in healthcare.* The other set of publications studied ethical issues related to usage of social media in healthcare. In particular, they focused on its influences to the patient-physician relationship. Gholami-Kordkheili et al. provide a review on the impact of social media on medical professionalism [16]. They identified opportunities and challenges of social media usage in healthcare. Beyond, ethical considerations concerning the relationship between patients and health professionals in the Internet era were included into the review. These include (1) preserving patient privacy and confidentiality in all environments, (2) avoiding excessive self-disclosure by using adequate privacy settings, and being aware that they are not absolute, and (3) routinely monitoring ones online presence. They claim that appropriate patient/physician boundaries need to be maintained, and in doing so the professional and personal online content should be separated [16].

Blake et al. summarised physicians and patient's usage of social media as well as ethical issues [17]. Among these are physician licensure, credentialing and privileging, liability (including medical malpractice), reimbursement, and privacy and confidentiality issues. They report about guidelines for physicians who use the Internet in their practices. Among these are the need for informed consent to collect, share or use personal data and a requirement for the physician to provide meaningful opportunities for patients to give feedback about their concerns. Similarly, St-Laurent-Gagnon and Coughlin provide recommendations for Internet conduct and virtual networking for paediatricians [18].

Jent et al. examined the prevalence with which healthcare providers use a social media site (SMS) account (e.g., Facebook), the extent to which they use SMSs in clinical practice, and their decision-making process after accessing patient information from an SMS [19]. Healthcare providers generally believed it not to be an invasion of privacy to conduct an Internet/SMS search of someone they know. A small percentage of trainees reported a personal history of conducting an Internet search (18%) or an SMS search (14%) for a patient.

### 3.2. Viewpoints of IMIA Social Media Working Group

In the following, we summarise the answers to the three questions that were posted through the IMIA SMWG mailing list. The questions concentrated on ethical aspects of internet research and usage of social media for public health monitoring and thus address the initial question.

*Privacy issues.* Privacy issues related to personal and health information are very important in any kind of environment, platform and means of communication (such as EHR, e-mail or social media). Several, similar ethical and legal guidelines should be considered in all means of communication and related research. There is no difference between health organisations and researcher when monitoring social media and data exploitation: the same ethical and confidentiality rules must be applied in both cases.

An important point is that, in theory, people know that personal information included in social media platforms, can be shared and accessed by anyone on the Internet, at least in open platforms. Another important issue is the fact that social media environments can be managed with different profiles and uses, for instance, open groups and closed groups on Facebook have to be managed in a different way in terms of confidentiality and privacy. Using data from closed groups need the administrator to be asked in order to gain access to its content. Ethically, the notion of de-identifying individuals becomes an issue. The recommendation here is to cite only indirectly from social media data.

*Responsibilities of health organisations and researchers.* Social media monitoring is a new field of research to gather health information that surely is not present in other more traditional and official sources of health information such as surveillance tools. When detecting any kind of health problem by means of social media monitoring, health organisations have to be prepared and take actions in order to manage the situation in the best way. Counselling, confidentiality and privacy aspects are critical points to be considered in each case, following ethical and legal guidelines in the application of the medical profession. Social media data alone is rarely enough to confirm a public health problem. Linking with medical professionals to correlate and corroborate the findings from the data with actual medical data is important. However, health organisations or researchers must balance the rights of subjects with the social benefits of research.

*Interpretative value of social media.* Mining text, detecting signals, mapping vocabularies are some of the tools that we have to consider when analysing and monitoring this social media data. People often use social media platforms to share information that is very difficult to get from other sources or is not present. The combination of different sources of health information, including the electronic health record, and social media may contribute to understand better the new health scenarios we are facing in personalised medicine, individual treatments or pharmacovigilance. However, relying only upon social media is not sufficient. It can provide additional information, but confirmation by means of official health data is crucial.

#### **4. Discussion and Conclusion**

In summary, the literature review resulted in ethical issues similar to those determined in the discussion with the working group members. Preserving privacy and confidentiality of online users is a main issue as well as providing means for patients or internet users to express concerns. For closed groups, the authority from the owner or administrator is necessary before collecting or analysing the data. Using aggregated data by researchers is acceptable to the community that created it. Health organisation should react when some hint to a public health problem is detected through social media monitoring. But they should not only rely upon that data. The interpretive value of social media data depends on the data analysis process. The data needs to be verified and corroborated with confirmed medical data to judge the interpretative value.

These results correspond to the three main principles for medical ethics introduced by Beauchamp and Childress [25]: autonomy, well-fare, and justice. When applying these principles in the context of health web science and public health monitoring from Web data, we need to consider that each person should have the right to decide about the usage of data and information concerning their private life – it is their right of

informational self-determination. On the other hand, the principle of well-fare and autonomy requires the availability of information about the efficacy of the detection methods.

In addition to the cited literature, there are organisations providing guidelines for internet researchers and health professionals. The Association of Internet Researchers (AoIR, <http://aoir.org/>), provide considerations to support and inform internet researchers about ethical issues [20]. The guidelines comprise a set of questions that should be asked by internet researchers or health organisations when they plan to use social media data for research and monitoring. Questions are addressing issues of potential harms or risks associated with a study, research methods, or storage and representation of collected data.

The American Medical Association (AMA) Code of Medical Ethics provides e-mail guidelines for physicians, which include the necessity to establish a patient-physician relationship in person, using e-mail only for supplemental encounters, and informing patients clearly about the inherent limitations of e-mail communication [21]. Also in this guideline, preserving patient privacy and confidentiality in all environments is a main issue.

The European Commission's Information Society Technologies (IST) Programme funded the RESPECT project [22] which drew up professional and ethical guidelines for carrying out socioeconomic research. The RESPECT guidelines reinforced the methodological challenges associated with online research (identifying dangers of conducting research in this manner) but stopped short of giving specific information tailored to the needs of online communities.

Despite some clearly identifiable risks, for example regarding the violation of privacy, it appears that public consensus on ethics will tend to override unscrupulous attempts to subvert the media [4]. The number of papers that could be included into our review was quite small. This was due to the limited number of existing research work indexed by PubMed on that topic. There was no publication dealing with ethical issues of public health monitoring using social media. This suggests, that ethical issues of social media usage in healthcare are just starting to come into the minds of researchers. On the other hand, PubMed might not be the best and only choice for determining literature on the ethics in medicine and social media research. Additional work is necessary to complete the review with other literature databases.

The extent to which social media is used in healthcare also increased mainly in the last two or three years. Our study showed that there is some awareness on ethical issues regarding usage of social media in healthcare. The focus of existing literature on that topic is on social media usage in healthcare. The answers from the social media working group suggest however that the ethical issues to be considered in public health monitoring from social media should consider similar ethical issues, mainly privacy. We are planning to create a questionnaire to collect additional viewpoints from medical social media researchers. Based on the collected input, guidelines for health web scientist will be created as part of the working group contribution to this topic. It is planned to extend the handbook of ethics for health informatics professionals provided by the IMIA [23] by those guidelines.

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