The Ethical Challenges of Social Media in Healthcare

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Abstract Social media have various advantages, such as reaching an extensive audience, low cost and prompt communication. However, at the same time there are risks in relation to misinformation and maintaining patient privacy. The main objective of this panel is to stimulate discussion about several aspects related to social media platforms, leading to the development of ethical guidelines about their use for health information and research purposes.

Keywords. Ethics, Social Media, Health services, patient-centered care, research

Introduction

Several topics related to ethics will be discussed around the use of social media (SM) in healthcare practice, health informatics projects and research. In particular, the subjects covered in this panel are: the integration of SM in clinical environments, the patient-doctor communication through SM, the integration of wearable technologies in health care, the use of SM for the recruitment into online surveys and the challenges of using SM for training elderly people and their caregivers.

This panel is an initiative of the International Medical Informatics Association - Social Media Working Group (http://imiasocialmedia.wordpress.com). The IMIA SMWG has already started the development of a survey on the ethical issues related to SM in the health domain (submitted to the IMIA Yearbook of 2015) and intends to develop guidelines on this topic in the format of a white paper. Presenters’ materials

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will be made available via the IMIA SMWG website and the content of the discussions will be captured. Participants who attend the panel will be invited (through the ongoing online discussion), to validate key points, thus contributing to the development of the ethical guidelines for health social media research. Chaired by Luis Fernández-Luque.

1. Integration of social media in clinical environments (Miguel A. Mayer)

The integration of SM in clinical environments is an open debate. The way that SM may be used as a tool to support communication between patients and healthcare professionals, how health information should be managed in the context of a clinical environment and the benefits and drawbacks of including this information in patient records, should be analyzed. Health providers and services have to rethink how to collect and secure the data generated in SM when including them in Electronic Health Records environments. Furthermore, patients would need to be educated about what kind of information is protected as personal health information and what is not. In addition, improvements in privacy and confidentiality will be critical to foster the use of social media and more experience is needed to determine its real clinical application.

2. Patient-doctor communication through social media (Kerstin Denecke)

Patient-doctor communication is strongly characterized by medical confidentiality, trust, and privacy. Data is expected to be safely stored in the patient record, inaccessible to others, and even protected by law. Does SM that finds its way into healthcare settings impacts this well established communication and interaction? The professional boundaries of interactions are less clear. Patients can access personal information from their treating physicians and vice versa. Will we be in future traced by our physicians online? Digitally tracking the personal behaviors of patients, such as determining whether they have indeed quit smoking or are maintaining a healthy diet, may threaten the trust needed for a strong patient-physician relationship and have an influence on their treatment of the patient. It is still an open question how to collect and secure the data generated by social-media tools when including them in a clinical and EHR environment.

3. Integration of wearable technologies in patient health and care (Margaret Hansen)

Wearable technologies and biosensors gathering personal data exposes individuals to a plethora of ethical issues. This rise in this technology and individuals looking to quantify themselves is interesting. An estimated 19 million items are predicted to be delivered in 2014 and up to 112 million products by 2018. This increase in personal data being generated poses ethical concerns about maintaining privacy of human data. The aim of this presentation is to discuss the three different types of wearables: (1) complex devices, such as fitness trackers; (2) smart accessories, such as smart watches requiring third party applications and; (3) autonomous smart wearables directly connected to the Internet, such as Google Glass. Highlighted in this discussion will be
ethical issues such as privacy and autonomy associated with the wearables that provide at any given time your geographical location, activity, and health data. These ethical concerns may be fading as we increase our use of wearables and desire to share with the world our personal accomplishments through the listing of health data (e.g. human heart rate before, during and after a marathon race).

4. Using social media for participant recruitment into online surveys (Mark Merolli)

Compared to traditional recruitment methods (i.e. study brochures), SM enables greater visibility and reach of online surveys. The result can be more efficient, faster and cost effective recruitment. However, this has ethical conduct implications. When combined with other online recruitment methods (i.e. email), SM have the potential to ‘layer’ the recruitment message and hence, build trust between researchers and research participants. Increased visibility of the recruitment message gives potential participants a sense of ownership over their eventual participation. Visibility and reach also have positive implications for reaching hard to contact target populations. In particular, stigmatized and at risk groups where a greater level of privacy and anonymity is favorable. Conversely, recruiting through online communities has ethical considerations that must be acknowledged. Contact from external entities can be pervasive and raise privacy concerns.Insensitive recruitment campaigns create barriers and mistrust in the research. SM based recruitment should not conflict with the principles of medical ethics.

5. Using social media to train the elderly and their caregivers (Panos Bamidis)

Recently, SM and internet content have been used to train the elderly by means of cognitive exercises and novelty serious web based games. Such methods are used as a way to prevent dementia but also to engage seniors into what is called “active and healthy aging”. What is more is that social media may be also used to train those that they care for senior people, be them informal or formal caregivers/providers. The aim of this presentation is to discuss the different challenges involved in these two endeavors: (1) senior (patient) recruitments and informed consents - the consenting process; (2) the use and exploitation of pilot data as well as social content interactions - open research data in active and healthy aging; (3) the social media and web content in creating training material-licensing content and creative commons and; (4) training and certification of caregivers on the web-social certification versus formal accreditation.

Expected outcomes of the panel: The discussion of this panel will help to identify the main ethical issues that researchers and other stakeholders need to take into consideration when conducting health-related research in social media. Many of those will also apply when providing health services in SM. These issues will be further elaborated in a white paper which can complement the current ethical guidelines (IMIA Code of Ethics for Health Information Professionals) established by the IMIA2.

2 http://www.imia-medinfo.org/new2/node/39