



Commentary

Ethical issues in using social media for health and health care research



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ABSTRACT

The dramatic growth of social media in recent years has not gone unnoticed in the health sector. Media such as Facebook and Twitter are increasingly being used to disseminate information among health professionals and patients but, more recently, are being seen as a source of data for surveillance and research, for example by tracking public concerns or capturing discourses taking place outside traditional media outlets. This raises ethical issues, in particular the extent to which postings are considered public or private and the right to anonymity of those posting on social media. These issues are not clear cut as social media, by their nature, blur the boundary between public and private. There is a need for further research on the beliefs and expectations of those using social media in relation to how their material might be used in research. In contrast, there are areas where the ethical issues are more clear cut, such as when individuals are active participants in research, where traditional considerations apply.

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1. Introduction

Health professionals are making increasing use of social media [1]. Uses include dissemination of health promotion messages [2], medical education [3–5], and dissemination of information at conferences [6,7]. So are patients, acting as sources of mutual support for others with similar ailments [8], although, in some cases, such as epilepsy, the role of Twitter is negative, promulgating stigmatisation of those affected. There are also concerns that some social media sites disseminate information that lacks an evidence base or contradicts established guidelines [9].

Given these increasing roles for social media, health researchers are also using it as a source of information, exemplified by the paper on the role of Twitter in the

debate on controversial health care reforms in England in this volume [10]. The term “infodemiology” has been coined to describe the surveillance of social media during outbreaks to identify and respond to public concerns [11]. Social media can capture emerging disease trends before official data are available [12,13]. Advances in data linkage, in which social media messages are combined with information on the location of the originator and the characteristics of the environment where they are located offer many additional possibilities [14]. The enormous potential has been revealed by disclosures about a product being manufactured by the defence contractor Raytheon, which exploits the time/date and geographical data embedded in messages and photographs posted on social networking sites to build up detailed pictures of individual’s daily activities [15]. Less controversially, it has also been suggested that comments on Twitter could be used to monitor the quality of healthcare providers [16].

There is a growing body of research in how to undertake research with media such as Twitter, both in terms of its

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content, for example to filter out the information that is wanted from the large volume of extraneous data [17], and to evaluate processes, such as the scale and direction of communication [18].

2. Ethical challenges

The nature of social media means that researchers can now “lurk” in wait for what are, in essence, ready-made data sets [19]. However, the speed with which these new sources of data have emerged, as well as the increasingly imaginative ways that researchers are using them, risked running ahead of the development of an appropriate ethical framework for their use.

Ethicists have recognised that they face a challenge in determining how to transfer traditional deontological principles into the world of social media, addressing the duties and obligations of the researcher, as well as how to deal with concepts such as utilitarianism, feminism, and communitarianism [20]. As research on material published on the internet involves no direct contact between the subject and the researcher. It avoids one of the problems facing much qualitative research, namely that of interviewer bias, whereby what is said is influenced by the researcher. However, the absence of such contact creates other problems, in particular those relating to informed consent and protection of the subject. This commentary considers two of the major issues in the ethics of social media research; the difference between public and private space and the right to anonymity.

Now that people routinely share detailed information on all aspects of their lives, including embarrassing anecdotes and even incriminating photographs on social media, there are questions as to what online privacy actually means. One approach is to apply the ethic of reciprocity, or Golden Rule, whereby the researcher asks how they would feel if the roles were reversed [21]. While the researcher might post information on his or her public profiles to be shared by friends or peers, this does not mean that they have consented for this information to be collated, analysed and published, in effect turning them into research subjects [22]. On the other hand, they may use their website to disseminate their work, in which case they will wish others to cite it.

A key consideration is whether information is considered as public or private. If public, then it is a legitimate source of research data, in the same way that a professional register [23] or a list of those receiving honours [24] may be used to examine certain characteristics, such as gender or country of qualification, of those included [25]. Yet, information on other characteristics, such as that obtained from the same subjects' tax returns, would be viewed as private in many (although not all) countries. This is a much harder distinction to make with online information, with some platforms having features of a public event (such as a rally or football match) and others like a private event (personal conversations). These dichotomised distinction are not very helpful when researching on the internet as the divisions are often indistinct and many interactions lie somewhere in between [22]. Although some interactions will more clearly be at one end of the spectrum, for

example in terms of the number of participants or explicit terms and conditions of use, this is not often the case.

These challenges have caused a revisiting of privacy norms associated with social media, where subjects' expectations are viewed as different from those in respect of communications off line or using email [26]. Specifically, there has been a rejection of the “anything goes” approach in social media research and acceptance that there are certain expectations of a degree of privacy by those using such media [27]. The challenge then is to operationalise this principle. How do people's expectations of privacy change depending on the type of media they are using and what are the consequences for researchers' ethical obligations [28]? This discussion recognises that the concept of privacy is inherently complicated and there is a need to understand how individuals will respond to violations in different contexts [29].

A related issue is that of anonymity. Anonymity is a fundamental right of subjects of research. It underpins the potentially fragile trust between the subject and the researcher and is integral to consent and provision of information as well as being a manifestation of the respect in which the researcher holds the subject in front of the computer screen. The use of online material as data intensifies the challenges that exist in traditional settings. Thus, a quotation from an interview need not identify the subject but, if from a Tweet, it can be traced back to the subject in seconds using Google [22]. Moreover, even when someone posts a message anonymously, it is relatively easy for a determined individual to trace that person through information such as their IP address [30]. This creates many additional ethical considerations for the researcher [28,31].

3. Potential responses

There are a number of measures that can be taken to address these concerns. One is to avoid quoting directly from a source that is publically available but rather to paraphrase it [22], although, as this interferes with the integrity of the data it should be noted that this has been done and it should be recognised that this could introduce bias. Where it is necessary to use direct quotes or to cite names or pseudonyms, Lawson argues that informed consent is necessary [32]. However, this seems somewhat simplistic. First, in many cases, such as the Tweets reproduced elsewhere in this volume, it is apparent that the initiators expected, and in many cases, wished them to be quoted. In essence, they were speaking publicly to advocate a particular position. Second, this fails to address the issues that arise when researching activities that are illegal, immoral, or politically controversial. For example, is it necessary, or even appropriate, for a researcher examining racism to obtain consent from those posting extremist comments?

There are, however, less contentious matters. Thus, when individuals participate anonymously in experimental studies, such as those in psychology, but where the IP address is collected, this can reveal the identity of the subject. It seems evident that this should be deleted before the information is published [33], something that will be of increasing importance given ongoing campaigns for publication of clinical trial data. This is a real concern, as seen

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