

Ethical Considerations When Using Social Media for Research

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Because of its adaptation across age groups and populations, social media is being used as a venue for the conduction of research studies. The implications for use of social media to streamline data collection and analyses to understand epidemiologic effects of disease are intriguing. Public access to personalized Internet-based searches and conversations for patients with or at risk for cancer can potentially allow providers to target individuals for earlier interventions and improved outcomes. Although publicly posted, the use of personal information to solicit research participants, implement interventions, or abstract information for research studies raises questions regarding maintaining the ethical conduct of research.

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About 25% of the 7.5 billion people on the planet use social media (Chaffey, 2017). To put this number into perspective, today's social media users outnumber the entirety of the planet's population in 1900. Specific to the United States, about 80% of the population uses social media, which has become a rich platform for research data. Social media includes the contribution of materials posted on the Internet by public consumers that is accessible to others, such as that posted to Facebook, Twitter, LinkedIn, and numerous other platforms (Casañas, Comabella, & Wanat, 2015). Using posted data from social media sites for research has led to the creation of the terms *infodemiology*, which is evaluation of Internet-based health data, and *infoveillance*, which is surveillance of Internet use (Bragazzi, Dini, Toletone, Brigo, & Durando, 2016). Social media is also used frequently as a venue to solicit research participants and contribute to interventions. With the amount of data generated daily through social media, the potential to answer research questions that would take considerably longer through traditional means is tremendous. From an ethical lens, what does use of social media mean in terms of confidentiality, biased samples, and equality? In addition, what are the implications for the translation of social media-based findings to oncology healthcare practices?

Confidentiality

In health care, confidentiality pertains to patients' rights to prevent the sharing of clinical or health information (Harman, Flite, & Bond, 2012). When using data from social media, confidentiality is often maintained when large-scale infodemiologic studies are conducted. For example, the Internet has provided a means to globally track infectious disease outbreaks and pandemic situations (Bragazzi et al., 2016; Freifeld, Mandl, Reis, & Brownstein, 2008). One resource, HealthMap (www.healthmap.org), uses algorithms that process posted information to search for media and World Health Organization postings about disease outbreaks and maps them geographically (Freifeld et al., 2008). This type of data collection and evaluation is global, public, and informative without compromising individual health information. Other platforms, such as online social networks that patients may use as a forum for information and/or support, can also track how many individuals are affected and where they are located (Bragazzi et al., 2016). Without the participants' knowledge, contributing to a social media conversation can place them into a research study that they may have declined if approached by the research team.

Another example is the use of posts on Twitter to conduct quantitative and qualitative content analyses. Qualitatively, words, phrases,