Ethical Considerations When Using Social Media for 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 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,
and underlying meanings of the content are analyzed for themes (Ha-
mad, Savundranayagam, Holmes, Kinsella, & Johnson, 2016) like they
would be from transcribed interviews. One challenge is interpreta-
tion of shorthand terms posted, which can have multiple meanings
(Weeg et al., 2015). Quantitatively, variables of interest can be put
into numeric form and analyzed. In traditional research, potential
study participants would be approached, introduced to the study,
proceed through the informed consent process, and agree to provide
the information for the purposes of the study. Gathering posted infor-
mation on social media bypasses all of these steps, including the
individual’s knowledge that his or her information is being used for
research purposes. Under the tenets of ethics, this is questionable.
However, those posting information do so knowing it is an open public
forum; therefore, researchers may conclude that consent is implied
for the use of the postings for any purpose. Regardless, such conclu-
sions are questionable.

**Biased Samples and Equality**

Social media is becoming a fre-
quent venue for recruiting research
participants of all ages. The notion
that older adults are less likely to
use social media is shifting as these
“silver surfers” adapt to the tech-
nology (Casañas et al., 2015). With
the largest percentage of patients
with cancer being aged older than
65 years (Howlander et al., 2016),
the use of social media is feasible
for oncology research studies that
include this age group. Advantages
of using social media for recruit-
ment are that it is much more far-reaching
than the geographic parameters of
an in-person study, the timing is at
the convenience of the (potential)
participant without having to co-
ordinate schedules, and it is more
economic (Casañas et al., 2015).

There may be variability, however,
in the study information reaching
individuals within the study popu-
lation of interest, particularly those
with limited or no Internet access
(Morrissey, Kinderman, Pontin, Tai,
& Schwannauer, 2016). In addition,
self-selection may bias the sample,
possibly to a greater degree than
a potential participant being
approached by a member of the
study team (Morrissey et al., 2016).
Self-selection is inherent in Internet-
based studies and is dependent
on the geographic location of the
targeted study sample, access to
the Internet, use of social media
platforms (e.g., Facebook, Twitter)
by the researchers, and potential
participants’ search and/or interest
in the health condition under study.
Researchers can also target spe-
cific individuals through their own
networks and ask participants to
share the study information to those
networks, creating a snowball sam-
pling effect. As with all studies, it is
important to remember to disclose
sampling bias when disseminating
findings. If the targeted population
is one that predominately has ro-
bust Internet access with a high use
of social media, such as within the
United States, studies may reach a
more representative sample of the
target population than traditional
methods of recruiting. With the pace
at which social media is becoming
a mainstream research tool, it may
soon be a traditional approach.

**Data Sharing**

The Internet has been a source
of health information for consum-
ers for more than two decades.
Differentiating accurate information
from misinformation has been chal-
llenging for healthcare profes-
sionals whose patients may seek
treatments based on unreliable
information found on the Internet.

However, the Internet has also
become a platform for providing ro-
bust discussions within and between
researcher and clinician groups
(O’Leary, Zaheer, Redmond, & Cor-
rigan, 2016). Conducting literature
searches using the Internet also
saves time; historically, searches
were done through hours of comb-
ing through library stacks of journals
and making forest-sized collations
of photocopied articles. Current lit-
erature searches using the Internet
allow for the most up-to-date peer-
reviewed articles. In addition, the
Internet has become a resource for
researcher data sharing and a venue
for creating large datasets through
which numerous research questions
can be answered (Lau et al., 2011).

One widely used area is the open
sharing of tumor-based genomic
data compiled from multiple studies
with consenting patients (O’Leary
et al., 2016). These big datasets
contribute to multiple subsequent
time-efficient, cost-effective studies.

Data sharing on a more personal
level without patient knowledge is
becoming a more common source
for answering research questions.
Health-related social networks
have even become a resource
for researchers to obtain patient-
reported outcomes, including effects
of pharmacologic therapies, without
patients enrolling in such studies
(Lau et al., 2011). The implications
for this are interesting. Through an
ethics lens, patient information is
used without consent. From a clini-
cal lens, however, it is possible that
information posted is more accurate
than enrolled patients responding to
questions, which may be influenced
by fear of reporting side effects that
can truncate therapies. Researchers
could elucidate this by conducting
a two-armed study comparing out-
comes between enrolling patients
and following side effects to similarly
matched patients posting to health-
related social networks.

**Translation to Practice**

In oncology, the primary goals of
research are to improve the lives
of patients with cancer and to ultimately prevent cancer from occurring. Information exchanges between members of the healthcare team and patients through social media is termed digital engagement (O’Leary et al., 2016). The use of digital engagement through mobile applications to foster dialogue, serve as health-related task reminders, and monitor patient activity has the potential to streamline clinical activities and may produce more robust data that can be analyzed to further improve protocols and outcomes (O’Leary et al., 2016). Digital engagement as part of clinical practice has infinite implications for healthcare management, but the potential for exposing personal health information is increased even with protective mechanisms. Clear definitions for timing of data evaluation need to be established because data are continuously being generated.

Conclusion

The use of social media for observational and interventional studies is likely to become a standard method for healthcare research in the future. Methods for the collection of valid and reliable data through social media have yet to be established (Mamlin & Tierney, 2016). Reaching populations with poor access to social media is a challenge. In addition, upholding the tenets of the ethical conduct of research needs to be examined and updated to meet the challenges that this technology provides. Internet-based technology is evolving so rapidly that it may become a challenge to maintain consistency in research methods.

References


Authorship Opportunity

Research Ethics addresses issues of ethics in writing for academic purposes. The column strives to address common problems found in research. Materials or inquiries should be directed to Associate Editor Marilyn J. Hammer, PhD, DC, RN, at marilyn.hammer@mountsinai.org.