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Ethics of Recruiting Research Subjects Through Social Media

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Bhatia-Lin and associates [2019] consider ethical and regulatory issues when social media platforms are used to track and locate research subjects who were recruited during hospitalization. They mention using social media for recruiting research subjects only in passing, but this aspect warrants deeper exploration. An important value of social media platforms is that they can cast a broad net in providing generalized information, allowing researchers to recruit otherwise inaccessible participants on a global scale. Insufficient enrollment accounts for up to 60% of delayed or incomplete clinical and translational investigations, which significantly impedes scientifically valuable research [Gelinas et al. 2017]. When an investigation is canceled or its conclusions weakened by insufficient enrollment, subjects are unfortunately exposed to risks, burdens, and inconveniences for little positive benefit.

The use of social media opens the door to the potential for a wide variety of information to become publicly accessible, including availability of research studies. Protecting confidentiality and privacy is a duty owed to possible research participants. Yet, these duties become challenging to meet within the arena of social media, as compared to institutional databases and highly secured electronic medical records.

While some recommend that social media recruitment ought to be assessed in the same manner and with the same general ethical principles as traditional recruitment [Gelinas et al. 2017], i.e., principles stemming from the Belmont Report, investigators must be particularly sensitive to such ethical issues as a timely and properly executed informed consent process, the need for transparency, and protection of vulnerable subjects. Social media posts by recruiters must be clearly descriptive and accurate in order to avoid misleading potential research participants. To ensure appropriate ethics oversight, research protocols sent to institutional review boards should describe in detail the intention to use social media as a recruitment tool and the recruiting methods that will be employed.

Informed Consent

The right to be informed originates from both legal and ethical principles that establish an individual's autonomous right to decide what happens to his or her body, as well as respect for privacy based on respect for persons and beneficence. Consent forms protect both

participants and researchers, and seek to provide potential research participants with the information necessary to make a voluntary and adequately informed decision to accept or reject participation. Social media platforms offer a unique advantage for recruiting research subjects: they can provide enough information to attract the attention of individuals who might be interested in participating in a particular study, then further provide sufficient additional descriptive information to constitute a sound basis for interested parties to make a decision to accept or reject participation.

The online consent process is substantially different from hospital or office recruitment as face-to-face explication of the information contained in the consent form is lacking. Even if audiovisual teleconferencing is used, important interpersonal signaling such as may be conveyed by body language is likely to be substantially reduced. This places a special burden on the written consent form for transmitting critical information to potential research subjects.

In today's online, social media-driven society, Internet users have been conditioned to "agree" without reading the fine print [Kosinski et al. 2015], thus putting participants and researchers at risk in the informed consent process. This conditioning may also be influenced by the fact that the average person's reading comprehension is far below that required to fully understand consent documents that too often contain complex words and syntax as well as legal jargon. To anticipate and minimize subjects automatically consenting without reading and understanding the details, researchers should design consent forms in a reader-friendly manner, highlighting the essential information in large print and short sentences, and with bullet point formatting where appropriate. Consent should not be burdened with legal jargon, complex words, or advanced-level and lengthy writing style, that serve to protect the interests of researchers and educational institutions rather than to inform the subject being recruited [Ferrigno and Sade 2017]. These factors combine to undermine adequate comprehension.

To achieve a valid informed consent, a consent form should be written at a 7th to 8th grade reading level and contain information that is material to the decision to be made [Pandiya 2010]. A properly constructed consent document for recruiting subjects should contain sections concerning: (1) the purpose of the research to which the individual is consenting; (2) detail as to what the research involves; (3) possible risks, benefits, and unknowns related to the research; (4) reasonable alternatives; (5) how the subject's information will be kept confidential, used, or disclosed for conducting research; (6) available options; (7) procedures for the subject to refuse further participation after being recruited; and (8) relevant contact information for answering questions [Beskow et al. 2010]. To provide a readable and simplified consent form, a supplemental document that includes additional information relevant to the research but not essential to the requirements of informed consent may be beneficial and is recommended to enhance the overall validity of the consent process and subject's understanding to what he or she is agreeing to [Ferrigno and Sade 2017].

Beyond the general requirements for consent forms noted above, special considerations become relevant when subjects are recruited on social media platforms. Consent forms should indicate the types of personal information that will be retained from subjects' social

media pages. Availability of subjects' data and their willingness to participate in research do not grant researchers the automatic right to use information on subjects' social media pages for research purposes without explicit consent. Participants should always retain control of what information may and may not be extracted from their social media accounts, including the right to retract any information that researchers have collected based on previously obtained consent.

Transparency

Transparency is a principle that must be upheld irrespective of the medium of communication and is owed to potential research subjects as a matter of respect. In addition, transparency in providing research information promotes both individual and public trust in the context of conducting research, thereby increasing the likelihood of subject recruitment and participation.

Posts to social media describing aims, risks, and benefits of research studies must be presented in an accurate and honest manner, including all information that is material to the proposed research study. Every effort must be made to avoid misleading potential research subjects with vague or deceptive language. Researchers must assiduously resist the temptation to configure the facts in a manner that appeals emotionally to social media users. Postings should be updated with any new information that comes to light, and misstatements made in previous postings should be disclosed and corrected in a timely and forthright manner.

Personal information posted to social media is relatively easy to view and collect without disclosure to an unsuspecting user. Even if information is posted on an unrestricted public social media platform, however, the requirement for transparency forbids lurking or stalking as ethically unacceptable — researchers must openly disclose their presence when searching for potential research recruits on social media platforms. Additionally, transparency requires recruiters to refrain from creating fabricated or disguised identities to gain access to persons or online communities that share common characteristics, such as cancer survivors or those who suffer from rare diseases.

Vulnerable Patients

Respect for persons requires that vulnerable populations have additional protections. In the context of research recruitment on social media, vulnerable subjects may include those who suffer from conditions or diseases that are rare or not readily treated with standard procedures. Approximately 8% of subjects involved in research found the trials in which they are enrolled by searching social media platforms [How do patients find clinical trials? 2015]. Ethical issues may arise when patients suffering from rare diseases or conditions that are not readily treatable are interested in becoming research subjects, because for example, about 69% of those with rare diseases suffer from depression, while 82% experience anxiety and stress. Delayed diagnosis and lack of standard treatment and control over their lives can at least partially explain such statistics. Additionally, patients with rare diseases who have survived to adulthood have likely suffered tremendously and faced a reduced quality of life,

or even may be approaching death. As posts on social media have the potential to mislead even when deception is not intended, recruiters must be cautious to avoid posting statements that could be misunderstood by vulnerable patients in search of hope for some type of cure.

In conclusion, though eager to increase enrollment in clinical and translational investigations, research recruiters must use social media cautiously, keeping ethical considerations in mind. Out of respect for individuals, special efforts should be made to avoid misleading vulnerable patients. Investigators must recognize the need for transparency in all aspects of online research recruitment, and their presence on social media must be plainly visible at all times to facilitate both individual and public trust in the research enterprise. Most important is the need for properly obtained consent that is based on information that is not only clearly expressed but, more crucially, is also understood.

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