Baystate Health

Using Social Media in Human Subjects Research: Risks, Benefits, and Best Practices

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Social media has become a valuable tool for researchers because it provides new ways to access the public and collect data. As its use has grown, Institutional Review Boards (IRBs) are seeing more studies that rely on social media to achieve study outcomes. Social media may be used in research in several ways, including data collection, participant recruitment, and participant interaction. Some examples of this are: analyzing social media content for public data, employing social media for targeted recruitment, and using social media for research participant support groups or discussion forums. Each use raises different ethical and regulatory considerations.

Ethical Issues

Let's begin with the ethical issues around social media data. Recent research shows that social media data often includes identifiable information and is frequently used without users' knowledge or consent. These risks may be even greater for vulnerable populations (3). Additionally, users may not realize their posts are being used for research, and some studies using social media data are conducted without appropriate IRB review. This poses additional problems such as the fact that researchers may violate the platform rules without realizing it.

There are also equity concerns. Social media use varies across demographic groups, and digital access is not equal. As a result, relying on social media for recruitment may lead to biased study samples. Some researchers may also not be aware that social media recruitment materials, including posts and targeted advertisements, are typically considered recruitment tools and must be reviewed and approved by the IRB.

Risks in Participant Interaction

Using social media for participant interaction raises additional concerns. When it comes to using social media for research participant discussions, such as Facebook groups, the Secretary's Advisory Committee on Human Research Protections (SACHRP) identified participant safety and scientific validity as the primary areas of concern (2). Regarding participant safety, social media discussions may: influence subjects to drop out when it is not in their best interest, spread misinformation about risks/benefits, lead subjects to guess their treatment assignment, and encourage oversharing of protected health information. Regarding scientific validity, social media use may: unblind subjects or

study staff, allow eligibility criteria to be shared publicly, influence outcome reporting, and discourage adverse event reporting (2).

Potential Benefits

Despite these risks, social media can offer important benefits. For instance, social media use can help improve identification of side effects, enhance recruitment and retention, support participant engagement and provide real-world insights. The key is for study teams to follow clear best practices when using social media.

Best Practices

Best practices in research involving social media use begin with referencing organizational social media policies **BC 6.815 - Social Media Policy and BC 6.815 Social Media Policy Attachment A Facebook Group Guidelines.** All social media advertisements that include the Baystate Health Logo must be approved by Baystate marketing before they are submitted to the IRB. All patient-facing materials must have IRB review before posting. In addition, investigators should review the platform's terms of service, as certain data collection practices may be restricted or prohibited.

Study staff must also be educated about the risks and benefits of engaging in social media for research. PIs must ensure that study teams are not utilizing personal accounts for patient/participant interactions of a professional nature. The PI must clearly lay out in the Protocol and IRB application who will be monitoring the account, who has access, and the period of access.

Participants should be educated about the risks and benefits of participating in research and engaging in it on social media. Social media use must be clearly addressed in the consent form, including expectations for participant behavior, potential risks, and any planned monitoring or restrictions. Investigators must also clearly explain unblinding, misinformation, and privacy concerns. When implementing these measures, investigators should balance participant privacy, study feasibility, and respect for autonomy.

Regulatory Considerations

The following are the federal regulations that most commonly affect the use of social media in research projects and should be considered when writing a research protocol and participant-facing study materials:

- Risk-benefit determinations (45 CFR 46.111)
- Informed consent and withdrawal rights (45 CFR 46.116)

• Equitable subject selection (45 CFR 46.111)

• Ongoing data and safety monitoring (45 CFR 46.111 (a)(6))

The bottom line is that social media introduces both risks and opportunities in human subjects research. Research teams should prioritize education, transparency, ethical review, and participant autonomy while adapting protections to the realities of the digital environment. The table below provides practical recommendations for using social media responsibly in research.

Recommendations for responsible social media use in human subjects research (1).

Domain	Action point	Description	Example
Recruitment	Assess and diversify social media platforms	Consider user demographics when selecting a social media platform to promote inclusivity	Use both Facebook (older adults) and Instagram (younger adults) for participant outreach
	Promote culturally and linguistically responsive strategies	Adapt messaging and platforms to fit cultural norms and language needs of target audience	Advertise studies in Spanish and English on social media platforms, when enrolling both these populations
	Engage community gatekeepers	Collaborate with advocacy organizations and community groups to improve trust and potential reach	Partner with a local patient advocacy group to share information about the research via their established online social network
	Minimize the use of sensitive targeted advertising	Use Online Behavioral Advertising (OBA) ethically and transparently, avoiding targeting based on sensitive characteristics	Avoid using advertisement mechanisms that target users by race/ethnicity or health status, unless this practice is justified and has received specific IRB approval

Retention	Support digital literacy	Help participants navigate digital platforms, reducing exclusion due to digital literacy	Provide step-by-step guides to help participants complete study activities
	Develop trust-building measures	Conduct community feedback sessions through the life of the study to build trust in research	Host a question-and-answer session with community members about the study's use of social media
Data Privacy	Disclosure data collection procedures	Implement public disclosures about research and data use on platforms when possible	Pin a post to a study social media page that outlines data collection practices
	Remove personal information	Take steps to de-identify data collected from social media	Strip profile names and geolocation from data prior to analysis
	Implement privacy safeguards	Securely store and limit access to identifiable online user data	Use encryption for databases storing participant social media data
	Review privacy practices for third-party vendors	If using a third-party vendor for data collection purposes, evaluate the vendor's data security measures	Choose vendors that are accredited with recognized standards
	Consider contextual privacy expectations	Determine if social media users expect a post to remain within the context of the platform	Do not assume that a publicly available social media post is appropriate to treat as "public" without further consideration

Works Cited

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