

GUIDANCE #: G-008

GUIDANCE: Social Media & Research

Revision date: 3.15.22

Guidance: The purpose of this document is to provide guidance to investigators and research staff concerning responsibilities and considerations related to the use of social media in human subjects research.

General Requirements and Tips:

1. Use this guidance document in conjunction with HRPP Internet-Based Research Policy (20.0) and PBRC Social Media Policy (112).
2. Investigators are encouraged to begin discussions with communications, legal and regulatory, and computing services departments before submission to the IRB. This will help mitigate issues, ensure compliance, and avoid major holdups with IRB approval.

IRB Submission

1. Include all websites you intend to use that are located outside of PBRC communication and recruitment departments.
2. Include a description of how potential participants will be identified and approached, and how privacy is maintained.
3. Describe the targeted population and the rationale for targeting that population.
4. Provide a plan for the frequency of messages, the method of communication, and the process for responding to incoming messages. A copy of the posts and planned responses will be reviewed and approved by the IRB.
5. Specify which study personnel will be charged with communicating and monitoring the recruitment account as well as any procedures to monitor the activity of those study personnel.
6. If an internet forum or group is required in the research, disclose who will moderate the group or send communication and with what frequency. Outline the plan for removing/addressing any inappropriate posts.
7. Specify if data will be collected as part of the recruitment process via social media.
 - a. If so, describe what data will be collected.
 - b. If that data is of a sensitive or confidential nature, describe how that data will be transferred and how it will be protected during transmission and upon receipt.
8. Provide a clear and concise summary statement regarding the intended uses of the internet or social media platforms as well as the guidelines and expectations for participation that will be provided to subjects via
 - a. an online participation agreement that subjects must read before joining or is pinned as an announcement or posted in another conspicuous place,
 - b. the consent document, or
 - c. a separate handout subjects must sign.

Informed Consent

1. When online research is being employed, the PBRC consent form template should be followed, unless a waiver or alteration of informed consent is granted by the IRB.
2. In general, investigators conducting Internet-based research with minors must obtain both child assent and parent permission. Researchers may request a waiver of parental permission, provided the study fits the appropriate criteria.
3. Participants should be informed of the potential risks in the informed consent document. For example:
 - Breach of confidentiality: There is a chance your data could be seen by someone who shouldn't have access to it. We're minimizing this risk in the following ways: [Use whichever of the following bullet points apply to your study. Add any other measures you'll use to protect data security.]
 - Your confidentiality will be kept to the degree permitted by the technology being used. No guarantees can be made regarding the interception of data sent via the Internet by any third parties.
 - Data may exist on backups or server logs beyond the timeframe of this research project.
 - Data is anonymous. – or – All identifying information is removed and replaced with a study ID.
 - We'll remove all identifiers after [insert amount of time or specific event].
 - We'll store all electronic data on the servers for the online survey software or at RCG.
 - We'll keep your identifying information [list. Examples include: your name, email address, IP address, etc.] separate from your research data, but we will be able to link it to you. We'll destroy this link after we finish collecting and analyzing the data.
 - Although every reasonable effort has been taken, confidentiality during actual Internet communication procedures cannot be guaranteed. Information shared via social media is not secure.
 - Online data being hacked or intercepted: Anytime you share information online there are risks. We're using a secure system to collect this data [elaborate if desired], but we can't completely eliminate this risk.
 - Add any other risks – think about emotional, social, and/or financial risks.
4. If applicable, include a statement that social media applications have their own privacy policies/terms of use and that they can view/edit these privacy settings in their own account.
 - Where participation in the study is contingent upon selecting a particular privacy setting or accepting a privacy agreement, clearly indicate that in the consent document.
5. If applicable, a social media disclaimer may be required. Please refer to Appendix A.

Post-Approval

If you wish to utilize a social media site for a previously approved protocol, an amendment is required.

Website policies and terms of use

Social media sites are typically governed by privacy policies and/or “terms of use” to which users must agree, at the risk of being removed from a site for noncompliance and/or subject to legal consequences. Terms of use state the rules of the website on a range of possible issues, including what types of interactions are expected and tolerated on the site, how personal information shared over the site may be used, which outside entities will have access to personal information for what purposes, and so on. Investigators must check that their proposed recruitment strategies comply with the policies and terms of use of the sites they wish to use and should provide documentation of HIPAA compliance with the assistance of legal and regulatory and computing services before submission to the IRB for review.

Privacy, trust, respect

Investigators should ensure that the proposed recruitment strategy is respectful of the community being recruited and will not undermine public trust in the research enterprise. For example:

- Investigators should not employ deception or fabricate online identities in order to gain access to online communities.
- Investigators should be fully transparent about the aims and details of a study when approaching potential participants, unless deception is deployed in compliance with HRPP Policy 19.
- Recruiters should not collect social media data about potential participants in ways unknown to the site’s users.
- Investigators should never reveal anything to a current or potential participant’s networked ‘friends’ or ‘followers’ that could let sensitive information be inferred about them (including their status as current or potential research participant), without the consent of the current or potential participant.

Managing post-enrollment online communication

Social media may facilitate post-enrollment communication between researchers and study participants, as well as communication between study participants (and potential participants) themselves. Investigators may develop educational materials to inform subjects about communications that may result in un-blinding or other adverse consequences (e.g., online postings containing detailed descriptions of the intervention and how it is affecting them, speculations about which arm of the trial they are in, posts regarding personal health information which indicate immediate harm to themselves and/or others).

Appendix A: Sample Social Media Disclaimer

Please note that this group is for educational purposes only and is not intended to dispense medical advice. Discussion of personal health information should not occur as this is not a HIPAA secure forum. For personal health questions, please contact your healthcare provider.

Please be aware that once you post something online, there's the potential for thousands of people to read your words, even years from now, even in a closed or secret group. As a result, we suggest that you exercise caution when posting information on any social media sites and that you not disclose personal identifiable information like your location, medical record number, financial information, etc.

While Pennington Biomedical makes reasonable efforts to monitor and/or moderate content posted on its social media platforms, we do not moderate all comments and cannot always respond in a timely manner to online requests for information. Please know we cannot respond to comments that deal with individual medical cases and issues.

IT IS YOUR RESPONSIBILITY TO BE FAMILIAR WITH FACEBOOK'S TERMS OF SERVICE AND ITS PRIVACY POLICY. YOUR PARTICIPATION IN THIS GROUP ACKNOWLEDGES YOUR RESPONSIBILITY RELATED TO THE SECURITY, PRIVACY, AND CONFIDENTIALITY RISKS INHERENT IN SENDING ANY CONTENT OVER THE INTERNET. BY ITS VERY NATURE, A WEBSITE AND THE INTERNET CANNOT BE ABSOLUTELY PROTECTED AGAINST INTENTIONAL OR MALICIOUS ATTEMPTS.

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