

# UNIVERSITY OF PENNSYLVANIA IRB

## GUIDANCE ON RECRUITMENT & RESEARCH USING SOCIAL MEDIA

### **Background:**

Social media offers researchers the opportunity to extend the reach of their recruitment efforts and to integrate novel approaches to data collection through sustained interaction with subjects. The continuously-evolving nature of social media, however, generates uncertainty for both researchers and IRBs regarding the management of risk to human subjects. Issues of privacy, confidentiality, informed consent and potential risks to subjects arise when researchers and subjects interact virtually. For example, a subject participating in research-related social media may mistakenly divulge personally-identifiable information in a public forum that they assume to be private or monitored by investigators.

However, through the development of a carefully-considered management plan, social media accounts can facilitate ease in targeting potential subjects and widen the scope of potential data collection. When appropriate and applicable for the study, the Penn IRB supports the use of social media in research. This guidance document is meant to serve as a resource to guide research teams considering the use of social media for research and to assist in the development of a management plan. Please note that the Penn IRB requires review of this comprehensive management plan before the initiation of research-specific utilization of social media.

In general, researchers utilize social media for two purposes: recruitment (both one-way ads & interactive recruitment) and as a component of the research interventions or data collection methods.

### **IRB Guidance on the Use of Social Media for Recruitment**

#### **Recruitment Ads:**

One-way ads that do not involve direct communication with potential subjects (i.e. paid Facebook Ads), are reviewed according to existing IRB review policies related to recruitment materials, as outlined in the [IRB SOPs \(Sec. 3.4.2\)](#). Please see the [IRB Guidance Document on developing recruitment materials](#) for more detail on permissible content and the IRB review process.

#### **Interactive Recruitment:**

Some study teams choose to recruit subjects through two-way communication via researcher-initiated social media accounts. This type of recruitment involves sustained and focused outreach to potential research subjects through direct messages on social media platforms (i.e. Facebook messages or Twitter direct messages).

Importantly, the IRB discourages study teams from establishing a social media account simply for the purposes of recruitment. Pilot initiatives led by the Penn Medicine Office of Communications found that study teams had little success in recruiting subjects through the use of Facebook pages and Twitter accounts. Isolated and sporadic recruitment messages, posts and tweets failed to kindle interaction that led to recruitment. The pilot study concluded this was due to the lack of a sustained, creative and focused plan for cultivating meaningful interaction with target communities. Moreover, the social media accounts were not online “destinations” for members of the target communities, and they struggled without this established foundation.

Please note that the IRB will consider this approach to interactive recruitment when research is conducted at a Center within the University that has already established itself as a viable online destination for communities from which researchers might want to draw potential subjects. Some examples of centers at Penn which have developed a well-maintained, self-sustaining and highly-trafficked online presence include:

1. **Penn Heart & Vascular Center:** [Facebook](#)
2. **Penn Pathology and Laboratory Medicine:** [Twitter](#) and [Facebook](#)
3. **Penn Memory Center and Alzheimer's Disease Core Center:** [Facebook](#)
4. **Penn Medicine Center for Healthcare Innovation:** [Twitter](#)
5. **Penn Social Media & Health Innovation Lab:** [Twitter](#)
6. **Penn Center for Aging:** [Twitter](#)

Consideration & IRB Review Requirements for Interactive Recruitment:

1. *Creating & Registering your social media account:*

Please consult the useful guidance offered in the [Penn Privacy Office and Office of Information Security's Guidelines for the Use of Social Media at Penn](#) and the [Penn School of Medicine Social Media Handbook](#) before creating your account. For research affiliated with PSOM, please register the account using the PSOM Social Media Proposal Form and indicate in your IRB application that you have done so. The PSOM Handbook and Proposal Form can both be found here (under Social Media)

  - a. For Centers, Institutes, Departments, or other groups (not individual faculty) aiming to develop a social media strategy should obtain approval from the [Penn Medicine Social Media Committee](#).
2. *What to include in the IRB application (in the Procedures section of HS-ERA):*
  - a. Please provide the text of researcher-initiated posts and planned responses. Please ensure that the language used follows the [IRB Guidance Document on developing recruitment materials](#)].
  - b. Please provide a plan for the frequency of messages, the method of communication (i.e. private Facebook messages) and the process for responding to incoming messages.
  - c. Please 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 personnel.
  - d. Please clearly describe the targeted population and rationale for targeting that population.
  - e. Please specify if data will be collected as part of the recruitment process via social media. If so, please describe what data will be collected. If that data is of a sensitive or confidential nature, please describe how that data will be transferred to Penn servers and how will it be protected during transmission and upon receipt.
  - f. Please describe how you will communicate to potential subjects during the recruitment process that information shared via social media is not secure. Please refer to the IRB-approved template language about privacy, confidentiality and social media which can both be found here (under Social Media) This information can be sent electronically to study participants. Alternately, the text may be posted visibly and permanently on your social media page.

### **IRB Guidance on the Use of Social Media as a Research Activity**

Some investigators choose to more broadly use social media as part of their research procedures, either for data collection or as a means of intervening with subjects for research purposes. Others use social media for more sustained communication with subjects, such as issuing appointment reminders. As these are innovative approaches to the use of social media, the IRB requires that investigators carefully consider a plan for protections that will be utilized for each social media application to minimize privacy, confidentiality and safety risks to subjects.

Consideration & IRB Review Requirements for the Use of Social Media as a Research-Related Activity:

1. *Creating & Registering your social media account for Perelman School of Medicine-based researchers:*  
(Please see instructions above in Interactive Recruitment)

2. *What to include in the IRB application (in the Procedures section of HS-ERA):*
- a. Please review the requirements for Interactive Recruitment noted above and ensure all applicable requirements have been addressed.
  - b. Please provide a clear and concise summary statement regarding the intended uses of the social media account as well as the guidelines and expectations for participation that will be provided to subjects. Please indicate how this information will be provided to subjects. This information might be communicated via 1) an online participation agreement that subjects have to read before joining, 2) the consent document, or 3) a separate handout subjects must sign. (Please see the [Guidelines for Participation in Penn Social Media](#) for an example.)
  - c. Please include a statement in the informed consent document notifying subjects that the 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, please clearly indicate that in the consent document. Please ensure the informed consent document is revised as needed to align with the privacy policies and terms of use agreements for these external applications, as they change frequently, and consider including a statement reminding subjects that these policies can change and should be revisited.
  - d. Please include a statement in the consent form outlining what will occur if any type of criminal activity, self-harm, sexual content, or any hateful/abusive content is discovered. The informed consent form and study should specify that the research will report any behavior to the social media site which does not align with the site's community standards.
  - e. Please specify if data will be collected as part of the research-related activity via social media. If so, please describe what data will be collected and indicate if any is of a sensitive or confidential nature, such as diagnostic information. Additionally, please describe how all data will be transferred to Penn servers and how will it be protected during transmission and upon receipt. Please specify whether any outside parties will have access to study data and the process for storing and/or transferring that data. If you have questions related to Penn security standards, please contact your team's local service provider.
  - f. Please indicate in materials provided to participants and in the social media forum that the study is voluntary. Specifically, please remind subjects that they can stop participating in this group at any time and outline the process by which subjects can withdraw their participation in any aspects of the study that involve social media including the collection/ use of their social media data for research purposes.
  - g. Please indicate in the protocol which study personnel will moderate the group or send communication and with what frequency. Please outline the plan for removing/addressing any inappropriate posts.

**If you have any questions about the IRB's policies on the use of social media in research, please contact David Heagerty ([heagerty@pobox.upenn.edu](mailto:heagerty@pobox.upenn.edu)) or Megan Bogia ([mbogia@upenn.edu](mailto:mbogia@upenn.edu)).**