**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.

Federal regulations consider direct advertising for study participants to be the start of the informed consent process. The VCOM IRB must review and approve any material or methods used to recruit study participants before that material is made publicly available.

When appropriate and applicable for the study, the VCOM IRB supports the use of social media in research. This 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 VCOM 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 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.

Generally, recruitment material should be limited to the following information:

* A statement that the study involves research.
* The condition being studied and/or the purpose of the research (e.g., “an investigational drug to determine if it may improve…”).
* A summary of eligibility (inclusion/exclusion) criteria.
* A list of potential benefits, if any.
* Location of the research site and the contact information

In all cases, use lay terminology.

When developing any kind of recruitment material, avoid language that could create therapeutic misconception and exculpatory language. Exculpatory language has the general effect of freeing or appearing to free an individual or entity from malpractice, negligence, blame, fault or guilt. Other unacceptable content for recruitment material includes:

* Emphasis on subject compensation.
* Misleading mottos or logos (e.g., “Tomorrow’s Drugs Today!”).
* Excessive repetition of words such as “free” or “at no cost.”

***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). The VCOM IRB discourages study teams from establishing a social media account simply for the purposes of recruitment. Pilot initiatives at other schools have found that study teams had little success in recruiting subjects through the use of Facebook pages and Twitter accounts.

**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.

What to include in the IRB application (in the Procedures section of the IRB Application Form):

1. Please provide the text of researcher-initiated posts and planned responses.
2. 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.
3. 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.
4. 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.
5. 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.
6. 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.