IRB Guidance on Using Social Media for Recruitment of Research Subjects

Use of Facebook, Twitter, Linked In, etc., for recruiting subjects is territory heretofore unknown to the world of research ethics. The University of MN IRB understands the powerful potential of using social media to contact and inform potential research subjects, but there are risks. This guidance is meant to point out and address some of the reasonable foreseeable risks using social media to recruit research subjects. Understand that this is new territory, the feds haven’t even weighed in yet, and that IRB will need to review each use of social media on a case-by-case basis and evaluate the plan for recruitment as in any other protocol. If and when federal regulations are revised to address the use of social media for recruitment, this guidance will be updated.

Most importantly you must remember that no social media site can provide absolute anonymity, confidentiality, or privacy. It is up to the researcher, when designing a protocol, to understand the various privacy and data security plans of the intended social media site to be used including how the data is transmitted and how it is maintained. The researcher must understand the privacy provisions set forth in the policies of a given social media Web site and be able to explain that information to both the IRB and the potential research subjects. Even if they are users of a given site, assume that people do not know the privacy and confidentiality policies in place. Data cannot be collected via social networking; this guidance is intended for the use of recruitment only. Other forms of guidance using social media to conduct research will be forthcoming in separate documents as needed.

There is a difference between participant materials intended to educate versus materials intended for recruitment. The IRB needs to review everything provided to research subjects in order for them to make an informed decision about participating the research project. Materials that were created to education patients about a given topic are no different if they are also being used to recruit research subjects. The IRB also needs to review participant materials regardless of when they are given to subjects, eg. as part of enrollment or as part of additional relevant information provided once a study is begun.

The materials can be prepared or funded either by the PI, an entity associated with the study such as a Community Advisory Board (CAB) or independently by an entity with no association with the study as long as the end result is reviewed by the IRB before its use. The same goes for distribution of the materials: funders, clinicians, participant peers can all be used to distribute study materials as long as this is included in the study design and approved by the IRB.

Materials created for use in multi-center studies are subject to review and approval by each local IRB. Local IRB review can either accept materials as is or require changes. The IRB needs to review for ease of subject understanding and appropriateness to the intended population, among other things.

The IRB needs to review all materials intended and designed for potential research subjects.