Evaluating Social Media Research: Ethical Considerations for IRBs
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Problem or Issue: More and more, IRBs are receiving for review and consideration protocols that involve the use of social media, either in the social behavioral disciplines or in the biomedical disciplines. In recent years, the amount of protocols that our IRB has been receiving regarding use of social media as a mean to gather and analyze information or data has been steadily increasing, particularly among graduate students, particularly in the social behavioral sciences field. We have found that most researchers feel that the use of social media provides a risk free environment as well as a fast, less burdensome way to gather data. But is that completely true?

Description of Program: During the pre-screening stage of a protocol, our IRB started to identify those that included social medial as part of the methodology in order to evaluate all processes from the recruitment and consent/assent phase, through the actual research phase and then the handling of the data and including security issues. More information regarding the use of social media in research was needed, so we started to look into it and offering training either through webinars or other means to the IRB members regarding the use of social media.

How it Was Evaluated: Protocol evaluation was divided in phases: pre-screening and the actual evaluation either by an expedited process or by a full review by the Board. During the pre-screening phase it was examined what media was used, it was reviewed if copies of the screenshots were included for review, the consent form or waiver of signed consent were evaluated to see if it complied with requirements, and whether it included sufficient information regarding the population to be studied. During the evaluation phase, all documents, questions, screenshots, and consent documents are evaluated more thoroughly, taking into consideration all aspects (according to rules and regulations) regarding confidentiality and privacy, how the data will be handled and stored, how risks are handled, and if there are potential benefits

Suggestions for Future Program Usage: For data management our institution is focusing on developing an organizational structure to include IT personnel to provide support to researchers about data storage and its handling, and how to make sure possible participants know that their input or other type of information is secure.

Review of Consent Process Suggestions: Multi-campus system with single IRB has centralized efforts regarding this matter.