Social Media

Social networking has changed the way we interact with friends and associates. Social networks such as Facebook, Twitter, YouTube, and Google+, play a significant role in our lives. Social media can be defined as any online and mobile resource that provides a forum for generating, sharing, or discussing ideas and content. Specific applications and web tools, many of which are free, are based on different, sometimes overlapping, themes and purposes, variably grouped as online communities (e.g., patient support groups, population-specific dating services); social networking (e.g., Facebook; Twitter); professional networking (e.g., LinkedIn); content production and sharing (e.g., YouTube, Tumblr, blogs); location-based services (e.g., Tinder, Grindr); and others. Many social media web services contain one or more platforms that allow users to view one another’s networks and interact with one another in real time. These include comment spaces, chat rooms, discussion forums, and the like.

In research, social media is most often used for recruitment. This method of recruitment is subject to the same regulatory and ethical norms as traditional recruitment, including the requirements of prospective review and approval, compliance with applicable federal and state laws, fair and equitable subject selection, respect for the privacy and other interests of potential participants, and sensitivity to the norms and values of different communities. That said, social media recruitment raises unique issues, including the ease with which personal health information can be accessed via these sites. For these reasons, greater care may be required to ensure participants are adequately informed of privacy risks.

Social media may also be used as a venue for participants to communicate with study staff and/or other participants. This carries several risks, including the risk that participants will be un-blinded because of someone’s description of their experience in the trial, and the risk of participants posting misleading information that undermines participant understanding of the study. Efforts should be made to inform participants of these risks and educate them on the importance of appropriate online communication while enrolled in the study.

To learn more about ways to protect yourself on social networks see: staysafeonline.org/stay-safe-online/protect-your-personal-information/social-networks.

Below are model statements investigators may adapt to describe social media recruitment.

**Sample: Facebook App**

Facebook will have access to the information collected through the app. In addition, Facebook will have access to any information that we provide to you using this app. You should also know that your individual Facebook privacy settings will determine who can see the app in your profile, your posts regarding the app, and if you invite your Facebook friends to participate. Your participation in the study may be made public. Facebook may reveal or confirm that you have participated in the study based on their policies and practices.

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