Top Considerations for Using Social Media in Research - It All Starts with a Plan
The use of social media by sponsors, sites, or investigators as a medium to advertise, interact, and retain research participants is growing in popularity. Social media is a powerful tool in that it not only allows for direct and continuing contact with participants, but the opportunity to build a community around a research project or a therapeutic area. There is, however, little to no guidance on how to approach social media in the research context and as a result this powerful tool is underutilized in the research community. The best approach to address this uncertainty is a comprehensive social media plan and early involvement of an IRB who has the requisite experience and willingness to embrace social media.
Is rationale provided supporting the use of each social media application?

- Social media is a potent tool which can have a lasting and wide impact on users. The rationale justifying the use of each social media application should be provided within the plan. A common rationale, and one likely sufficient in most circumstances, would be that the target demographic frequently uses the chosen application(s) and thereby the application(s) represents an opportunity to identify and connect with the target research population.

- The depth of rationale necessary may vary depending on the application’s characteristics, familiarity, and reputation. Facebook, for example, provides administrators options that help ensure the risks to participants can be minimized (e.g., user generated content can be disabled), is widely used by the public, and has a fairly good reputation. Twitter, on the other hand, only provides administrators the option of public versus private tweets, is not as widely used, and is generally viewed as a less reliable (truthiness) source of information.

Are the possible privacy and confidentiality concerns of each social media application specifically addressed?

- The privacy protections that will be utilized for each social media application should be addressed and as necessary the choice of privacy settings justified. For example, Facebook allows for the creation of pages or groups and for specific privacy and notification settings within each. A page is largely public, but can be setup such that all user generated content is disabled or reviewed prior to being shown on the page. A group can be public, private, or even secret and can be set to be invitation only.

- All communications provided and received within social media should generally be presumed to be identifiable and public unless specific measures have been taken to ensure privacy. All posts and communications should be vetted to ensure that users are not intentionally or unintentionally prompted to provide sensitive information that may affect their rights or welfare and a plan should be in place to remove, correct, or attribute any such communication.
Is there a standard articulated for distinguishing between communications that will be and will not be considered IRB reviewable subject matter?

- Communications that are directed toward the public and are specific to a particular clinical trial require prior IRB review and approval. This also means that these communications must be provided for review in the format they will be used.

- Communications that are not directed toward the public (medical professionals or investors) or are not specific to a particular clinical trial do not require prior IRB review and approval. These communications should be described in general terms by category—celebrity tweets, news stories, relevant publications—and representative examples of each should be provided.

Is there a process or standard for reviewing all communications to ensure that they are not harmful, misleading, or incomplete?

- All communications, clinical trial specific or not, should be vetted according to predefined standards for sensitivity and the possibility of unintentional duress, stigmatization, or other personal harm. For example, communications should be reviewed for any possible negative connotations for the user—a post linked to a story entitled “Cancer - Why There's No Cure” or a post linked to a HPV vaccine trial on a flu vaccine trial page.

- All communications, clinical trial specific or not, should generally be vetted as they will be posted. For example, Twitter’s 140 character space limitation does not allow for sharing of specific information related to clinical trial benefits or risks and thereby necessitates more general language or links to ensure that complete disclosures are always provided.

Is a clear and concise summary statement regarding the intended uses of the social media account provided to users?

- Users should be able to easily identify the purpose of the account, how it will be managed, and any limitations on how it should be used. For example, the “About” tab in Facebook allows for the administrator to add detailed page information including a short and long description. The short description may be used to describe the basics of the research trial itself and the long description may be used to describe that the account is intended to help build a community of interested persons, that the page will be monitored and the harmful, inaccurate, or inappropriate content will be removed, and that the page should not be used for medical advice or for reporting any study related events or other information.
The different social media applications have significantly different abilities in this regard, so a summary statement may not be feasible depending on the application utilized. The use of any such account should be appropriately tailored to match the lack of specific information that may be provided.

If users will be able to post user generated content, is there a management plan in place to monitor and possibly respond to or remove inappropriate information?

User generated content is often considered essential to a robust online community. If it is enabled, safeguards should be developed to ensure that user posts are routinely monitored and that action can be taken if necessary to ensure participant protection or study integrity. This can include predefined actions and communications that will be taken to address specific scenarios. For example, the management plan could include the rule that all possible adverse events will be escalated to a medical monitor for review and if possibly related to the trial removed immediately and a private message sent to the poster indicating that all study related events should be reported immediately to the study doctor.

A management plan could also include a cascading communication plan for anticipated posts, topics, or issues in which a sponsor would have the ability to “spontaneously” interact with participants based on participant responses. These communications would have to be fully formed and previously IRB approved and thereby ready for use in real-time without additional review.

There are many different issues to consider when designing a social media plan in the research context. The considerations provided here represent just a few of the lessons Quorum has learned. We trust that you may find them useful and look forward to working with you in the future to continue to promote the ethical conduct of research.
In 1992, Quorum’s founders saw a need for an IRB that protected human participants while providing high-touch customer service. That’s exactly what Quorum delivers. Each member of our team brings a wealth of experience in clinical research human participant protection—as well as the knowledge, reliability, accuracy, and speed that matters when getting products to market.

With a focus on performance, these are the core values that comprise Quorum’s foundation:

- Ethical protection of human research subjects
- Customer service
- Continuous quality improvement
- Promotion of organizational capability

Quorum Review IRB has been fully accredited by the Association for the Accreditation of Human Research Protection Programs (AAHRPP) since 2006. AAHRPP’s “Full Accreditation” emblem signifies that Quorum Review consistently demonstrates excellence in comprehensive protections for research participants while facilitating the highest quality research processes.