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Top Considerations for Developing a Research Social Media Plan

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DESCRIPTION

Social media can be a powerful tool to enhance the process of scientific medical trials, yet there is little to no guidance on how to approach social media in the research context. This whitepaper touches on some strategies to consider and potential pitfalls to avoid.

TOPICS

- THE USE OF EACH SOCIAL MEDIA PLATFORM
- PRIVACY CONCERNS
- IRB REVIEWABLE SUBJECT MATTER
- A PROCESS DESCRIBED FOR REVIEWING
- A CLEAR AND CONCISE SUMMARY
- A MANAGEMENT PLAN

Social Media Is A Powerful Tool

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 so this powerful tool seems to be 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.

The following is offered as a starting place for any comprehensive social media plan:

1. The use of each social media platform should be supported by adequate rationale.

- Social media is a potent tool which can have a lasting and wide impact on users. Rationale justifying the use of each social media platform should be provided. A common rationale, and one likely sufficient in most circumstances, would be that the target demographic frequently uses the chosen platform(s) and thereby the platform(s) represents an opportunity to identify and connect with the target research population.
- The depth of rationale necessary will likely 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 (user generated content 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 less reliable (truthiness) of a source of information.

2. The possible privacy concerns for the use of each social media platform should be identified and minimized as much as possible.

- The privacy protections that will be utilized for each social media platform should be proactively described 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/or communication 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.

3. IRB reviewable subject matter should be distinguished from non-reviewable subject matter.

- Communications are directed toward the public and are specific to a particular clinical trial require prior IRB review and approval. These types of communications will require prior IRB review and approval before they are 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 may be described and approved in general terms in the social media plan by category - celebrity tweets, news stories, relevant publications - and representative examples of each provided.

4. A process should be described 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."
- All communications 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.

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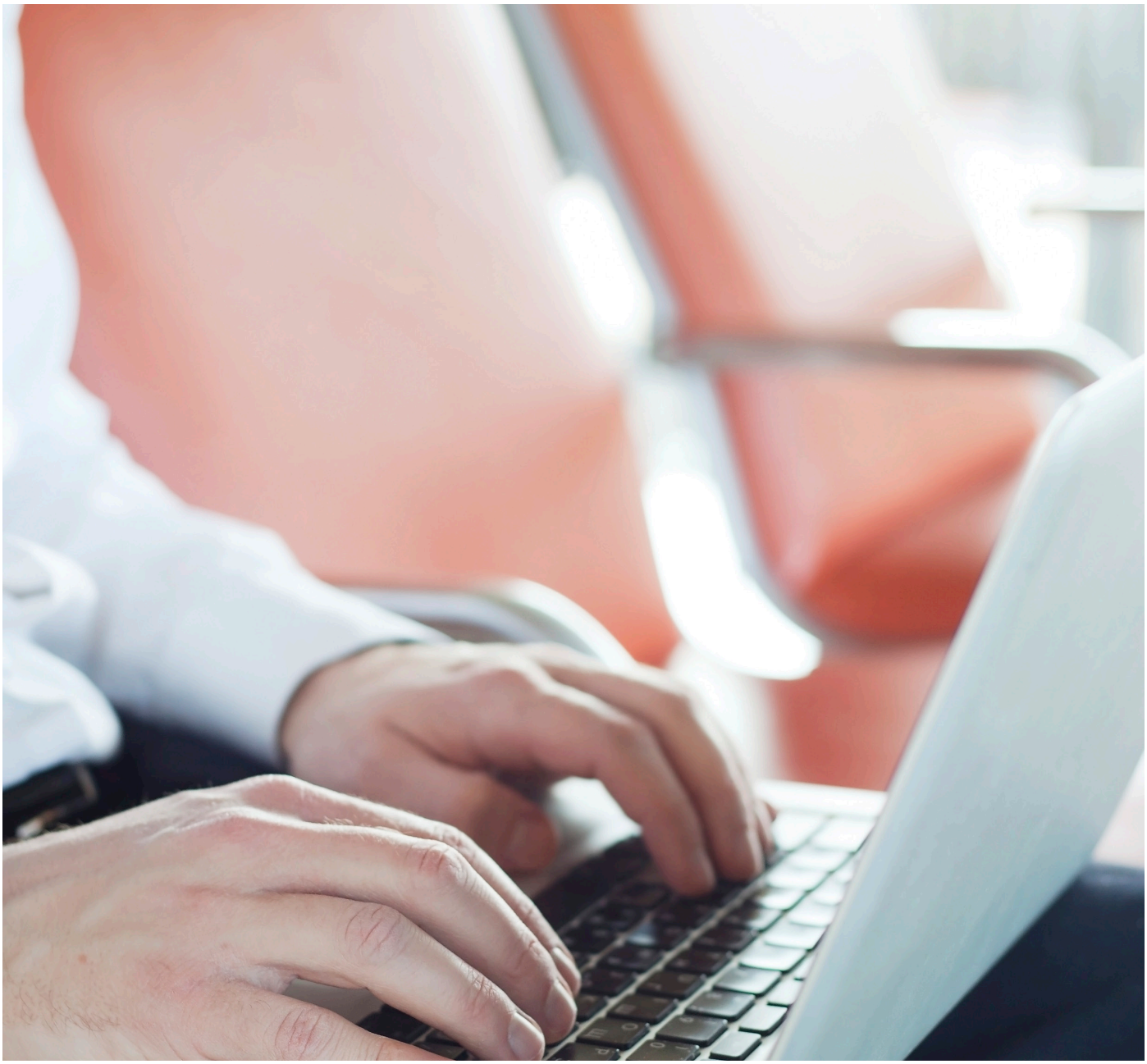

5. A clear and concise summary statement should be created that explains to users the purpose of each social media platform account.

- 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 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 and 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.

6. A management plan should be described for monitoring and possibly responding to user-generated content, if enabled.

- 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 related to trial participation, 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 context of research. The considerations provided here represent just a few of the essential components to a robust social media plan. We trust that you may find them useful in beginning to develop your own plans and look forward to possibly working with you in helping to promote a participant centered focus to clinical research and, in particular, the use of social media.

About Kinetiq

Kinetiq is a consulting and technology firm that delivers innovative solutions to the challenges of human subject protection and compliance in clinical research. We work with clinical researchers, research institutions, pharmaceutical, biotechnology and medical device companies as well as others around the world to develop contemporary approaches to a changing landscape.

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