



PEOPLE

Clinical trial recruitment through social media¹

Introduction

Recruitment through social media can be conducted passively through advertisements, posts, or flyers or actively where researchers interact with individuals on a social media platform. In either case, the IRBs/ECs should be provided with information describing the approach and plans to obtain consent and documentation of consent activity from participants.

Advice for Investigators/Sponsors Proposing to Recruit via Social Media

- Provide the IRB with a statement describing the proposed social media recruitment techniques, including:
 - A list of all channels/websites to be deployed in recruitment.
 - A script of the information, images, and format to be displayed or posted. (See information about eConsent content.)
- Describe recruitment methods:
 - Passive recruitment involves the distribution of recruitment materials (e.g., ads, posters, flyers) with the aim of attracting potential participants to contact the research team for more information and consideration of enrollment.
 - Provide all information, notices, and/or advertisements that are proposed to be posted about the planned clinical research. Include where such information will be posted.
 - Describe whether and how this recruitment differs from the placement of a notice in a newspaper, on a bus, or on other public site as might be done in a traditional clinical trial.
 - Active recruitment involves the interaction of research staff members with specific individuals with the aim of enrolling them in research.
 - Describe how research staff will identify themselves when entering and while on the social media site and upon engaging any specific individual
 - Attest that private personal and health information will not be retained, scraped, or stored from the site without consent.

¹ Adapted from: Gelinus L, Pierce R, Winkler S, Cohen IG, Lynch HF, Bierer BE. Using social media as a research recruitment tool: ethical issues and recommendations. *The American Journal of Bioethics*. 2017 Mar 4;17(3):3-14.



- Describe how potential participants will be identified and approached, and how their privacy and confidentiality will be maintained.
 - Describe the proposed elements of any planned conversation or interaction with potential participants.
 - Attest that screening for participation or exchange of private personal and health information will not be performed on the social media site.
- Provide the IRB/EC with a statement certifying compliance (or lack of non-compliance) with the policies and terms of use of relevant websites.
 - If the proposed techniques **conflict** with relevant website policies and Terms of Use
 - Provide the IRB/EC with a written statement describing the apparent compelling circumstances that might justify IRB/EC approval, despite non-compliance with the website's Terms of Use.
 - If the IRB/EC requires the website to provide an exception from its policies or terms of use, the PI should provide the IRB with written documentation of the exception, if granted.
 - Ensure that the proposed recruitment strategy respects all relevant ethical norms.
 - Proposed recruitment should not involve
 - Deception or fabrication of online identities.
 - Members of the research team 'lurking' or 'creeping' social media sites in ways that members are unaware.
 - Advancements or contact that could identify, embarrass, or stigmatize potential participants.
 - Recruitment strategies should generally be designed such that:
 - The reach of the post is purchased rather than based on "likes," "sharing," "retweets," etc. since such behaviors might expose medical information unnecessarily to the extended network of the potential participant.
 - Any promotion of the link will transfer the potential participant away from the social media platform and to a website from which information is not shared or at risk of being shared with one's network.
 - Trials are accurately represented in recruitment overtures.
 - Potential trial participants found on social media are likely to engage on social media with some regularity. Therefore, a formal communication plan is needed for managing social media activities among enrolled participants, including:
 - Steps to educate participants about the importance of blinding and how certain communications can jeopardize the scientific validity of a study (e.g., a informational section in the orientation or consent form)
 - Triggers for intervention from the research team (e.g., misinformation or speculation among participants on social media that could lead to un-blinding)



- Interventions from the research team (e.g., corrections of misinformation or reminders about the importance of blinding on social media.)
- Consider making the posts only visible to group members to avoid medical information being shared (or imputed) when potential participants interact with the post.
- Ensure that the social media recruitment strategy complies with applicable country, federal and state laws.