

Clinical trials in the era of digital engagement: A SWOG call to action

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Krishna Gunturu, MD



Don Dizon, MD

Article authors Krishna Gunturu, MD, and Don Dizon, MD, are members of the SWOG Cancer Research Network digital engagement committee, and pose provocative questions about better ways to bring doctors, patients, and others together to talk about cancer trials on social media. Credit: SWOG Cancer Research Network

Social media is an integral part of medicine, and an increasingly important conduit for sharing information about clinical trials. In an article in *JCO Clinical Cancer Informatics*, researchers from SWOG

Cancer Research Network pose provocative questions aimed at sparking discussion and creating consensus on how cancer clinical trial stakeholders can best interact on social platforms.

Written by members of SWOG's digital engagement committee, the article notes the growing role that platforms like Facebook and Twitter play in raising awareness about [trials](#) and boosting their accrual. This significant promise—to make trials a larger part of the cancer care conversation and to make them more inclusive—is matched by significant legal, ethical, and logistical challenges for patients, researchers, institutional review boards, and trial sponsors.

According to the authors, these challenges include the risk of misinformation, the possibility of unblinding treatments used in trials, and the lack of clarity around regulatory oversight of [social media](#) content. What social content regarding cancer trials requires institutional review board approval before posting?

"With this article, we're raising the question: How can we best use social media to talk about cancer trials in ways that are meaningful, ethical, and engaging to every stakeholder?" said Krishna Gunturu, MD, a SWOG digital engagement team member, an oncologist with Lahey Hospital and Medical Center, and the lead author of the article. "To realize the potential of social media as a cancer trial educator and equalizer, we need consensus."

Specifically, the SWOG team asks:

- Is it time to ask study volunteers to sign a [code of conduct](#)? This may help prevent disclosure of data during trial conduct and analysis, thus ensure the integrity of clinical trial data. A code, or confidentiality disclosure agreement, could also help patients by specifying that they maintain access to their own trial data.

- Should social media be a required activity of a clinical researcher? The authors note that social media is an important way for researchers to directly engage with patients by sharing information, dispelling myths, and highlighting critical trials through direct digital conversation. To help, SWOG is creating social media toolkits to accompany new trials. The aim is to give study leaders access to IRB-approved information—text and graphics—that can be used in Twitter and Facebook posts as soon as their study opens.
- Is there an appropriate scope of IRB review related to social media use? SWOG members point out that there are no rules for what kinds of social content requires IRB approval, and when and how. It's also not clear what constitutes "active" and "passive" social media recruitment under National Institutes of Health social media guidance.
- How should sponsors collaborate with stakeholders on social media activities? Specifically, the SWOG team believes that patient advocates can play a critical role in public engagement in cancer trials. Advocates currently run a slew of Facebook and Twitter support groups for nearly every cancer type, and are often at the table when cancer trials are conceived and developed. Should trial sponsors do more to encourage patient advocate participation in social media?

"These are key questions, and we need to come together as a cancer clinical trial community to arrive at answers," said study co-author and SWOG Digital Engagement Committee Chair Don Dizon, MD, a professor of medicine at the Warren Alpert Medical School of Brown University and a member of the Lifespan Cancer Institute. "Our goal is to call everyone with a stake in cancer trials to action so we can use social [media](#) as a tool to advance [cancer](#) research."

More information: Krishna S. Gunturu et al, Clinical Trials in the Era

of Digital Engagement: A SWOG Call to Action, *JCO Clinical Cancer Informatics* (2020). [DOI: 10.1200/CCI.19.00128](https://doi.org/10.1200/CCI.19.00128)

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