



clinical trials social media

At the Crossroads of Social Media and Clinical Trials Executive Summary

Communities are connecting and growing through social media at a speed that is transforming patients' knowledge of and participation in cancer clinical trials. On June 7–8, 2018, more than 1,100 professionals—clinicians, researchers, health care providers, advocates, and individuals personally touched by cancer—participated in the At the Crossroads of Social Media and Clinical Trials conference sponsored by the National Cancer Institute (NCI) under the Cancer MoonshotSM program. Participants joined in person and by webcast to exchange knowledge and synthesize new ideas for improving education and awareness about clinical trials in the community through social media.

The conference was, to our knowledge, the first time such a group of diverse stakeholders has gathered to discuss ways to develop evidence-based communication strategies around the use of social media in clinical trials. Throughout the two days, many at the event shared their enthusiasm for being in an environment where they could interact with professionals in their field of expertise and others with whom they would not normally interact. Many ideas for collaborations and moving forward began brewing among attendees even before the conclusion of the workshop.

Several overarching themes emerged from workshop presentations and ensuing discussions, including the following:

- Seventy percent of Americans are now on social media (Pew Research Center 2018). This includes rural, young adult, and minority populations. Social media gives us an opportunity to leverage communities and resources to interact with a much broader community than we've been able to reach before.
- Patients should be considered research partners, not merely subjects, in trials. We are experiencing a "patient revolution," when patients want to have more say in their health care. Social media can help incorporate input from diverse patients and open two-way dialogue to improve trial design.
- Presenting clinical trials as a human endeavor can help combat stigmas associated with trials. Trials involve the efforts and participation of real people. Campaigns that show the very real humans behind

trials, including clinicians, patients, and researchers, could help counter concerns of potential patients and encourage better informed decision-making about participation.

- There is a need for more opportunities for advocates, patients, physicians, and other clinical trial stakeholders to come together. Collaboration and the exchange of expertise across professions is necessary to tackle longstanding challenges in patient outreach and trial recruitment.
- More clarity is needed on acceptable scopes of social media use for professionals. Many providers have expressed interest in communicating through social media, but they fear doing or saying something wrong.

Social Media: All on Board

With over 35 speakers taking the stage, all agreed that social media is one of the major shapers of national conversations on health care. Social media provides an opportunity to disseminate credible health and medical information, heighten awareness of clinical trials, and share information with and among health professionals. Patients, caregivers, survivors, and the public are routinely using social media to research and discuss health care issues. There are abundant examples of blogs, online community platforms, Facebook communities, and Twitter hashtag communities that offer hope, support, education, information, empowerment, and connections for patients and caregivers. These platforms have enabled patients to feel less alone and hold candid conversations with others who are facing or have faced similar health challenges. For example, there are many popular cancer support pages on Facebook today, including the Association of Cancer Online Resources, a system of over 200 online cancer communities with more than 1 million members.

It's clear that many cancer patients are online, embracing social media and adapting their information-seeking and information-sharing behaviors to the changing digital landscape. It is also clear that social media can play a major part in informing providers and patients about participation in clinical trials. Although speakers noted how some researchers, clinicians, and health care providers are adopting social media as a strategy to engage in conversations with one another and with patients, not all are doing this. An overarching question over the two-day workshop was how to encourage researchers and clinicians to understand and leverage social media more in their clinical trials communication endeavors.

Treating Patients as Partners

Many speakers, including patients, advocates, and clinicians, expressed the sentiment that there remains a lack of engagement in, and awareness of, clinical trials among the general population. This is especially true in minority and other traditionally underrepresented communities. Speakers also noted that there is a sentiment that patients are often seen as human subjects rather than partners in research.

On social media platforms, however, patients have been demonstrating that they are an important part of the clinical trial process. For example, PatientsLikeMe.com has leveraged its patient networks to inform a more patient-centric trial design (DasMahapatra et al. 2017). Through their inclusiveness they seek to consistently earn the trust of their community of over 600,000 patients.

Patient advocates at the meeting urged scientists and researchers to take advantage of the knowledge that patients offer online and via social media.

Speakers mentioned that clinical trial researchers can consider the following principles when engaging patients through social media:

- Establishing ethical guidelines for patient-researcher partnerships in social media interactions.
- Training doctors, researchers, and clinicians to use patient-friendly resources, and language that patients can understand, when communicating online.
- Creating connected online communities for patients enrolled in trials to enable peer-to-peer patient support and communication as well as facilitated discussions with clinicians when appropriate, depending on the trial design. Continuing discussions are needed on how to address social media dialogue in certain types of trials such as double-blind placebo controlled randomized trials.

Engaging Patients and Health Care Providers

For social media platforms to be effective in engaging and informing patients and providers about trials, the target audience should see themselves reflected in others taking part in trials. Surveys of patients and caregivers conducted by NCI showed that people were more likely to consider a clinical trial if it is offered as a possible treatment option for patients like them. Social media provides abundant opportunities to use multimedia tools to connect with online audiences.

Speakers recommended that online clinical trial communication efforts should:

- Show real people facing health concerns and include personal stories.
- Show a diverse group of people and diseases when discussing clinical trials.
- Offer “hope” but in a realistic manner that does not over-promise.
- Portray clinical trials as state-of-the-art medical research, not necessarily as cutting-edge technology.
- Avoid showing trial participants as “heroes” who take great risks that others might not.
- Communicate more clearly about trial opportunities—state a clear value proposition written in plain language and include contact information for potential participants to reach out with questions.

Speakers emphasized that each social media platform and channel is different, reaching different audiences with different network patterns. For example, Twitter is effective in driving traffic to other websites. For this reason, many organizations use Twitter to promote their website content, share information about clinical trials, link to educational materials, connect leaders with one another, announce new trials, publish results, and connect with advocacy groups. Facebook was said to be useful to highlight philanthropic partners, posting events, and highlighting general news on significant developments. One group shared that they use Twitter to target all stakeholders and Facebook algorithms to target patients and family caregivers.

Speakers also discussed how to engage health care providers. One way is by providing evidence of the benefits of using social media. There is evidence to show that patients are engaging online and using social media to find out information on their own. Health care providers can use this platform to engage the public and each other. According to one speaker, social media is good for broadcasting messages out to potential patients and amplifying good information.

Creating Trials That Represent Minority and Underserved Communities

Discussion at the two-day conference also focused on the lack of diversity in cancer clinical trials, enumerating challenges in addressing disparities in clinical trial participation in many underserved populations, including seniors, the LGBTQ community, Hispanics/Latinos, and African Americans.

Speakers noted advantages to using social media to tackle historical barriers in recruiting minority and underserved groups. For example, statistics show that seniors and the LGBTQ community are on social media; however, there are noted mistrust and transparency issues that may limit their participation, as does implicit bias in some doctors and researchers. For instance, doctors may be hesitant to offer trials to certain populations, such as older adults. Additionally, research has shown that patients from minority populations are not offered clinical trials at the same rate as their white counterparts.

If patients are not engaged in discussions about possible clinical trials, they cannot deliberate on whether to participate. Some possible strategies for connecting with underserved populations to encourage participation and trial success include (1) the use of targeted online ads on the most popular social media platforms adopted by those communities, (2) collaboration with existing patient communities on social media to facilitate connecting with vast networks of patients from targeted demographics, and (3) integration of the unique needs of certain underserved communities in the design of trial protocols.

Facilitating Use of Social Media in Clinical Trials

Addressing the challenges faced by researchers and clinicians in facilitating the use of social media in clinical trials, speakers suggested embracing the “language” of social media. For example, create graphics and hashtags and visually show clinical trials in categories, make application program interfaces available for network groups, create plain-language guidelines and trial templates, and share data, as appropriate, in a public domain. One speaker noted the importance of search engine optimization, claiming that not everyone is on Facebook or Twitter, but everyone has Google.

Conclusion

Many of the organizations represented by attendees, including NCI, have been using social media as a communication platform for years, but public awareness of clinical trials and their benefits to society remains low. There continues to be fear and stigma surrounding clinical trial participation. Many speakers suggested that the clinical trials community has an ethical obligation to increase patient engagement.

Building a social future for trials will require that stakeholders (researchers, clinicians, patients, and caregivers) leverage their use of various online platforms, cross-disciplinary collaboration, and metrics-based evaluation to more effectively connect with each other and the community about clinical trials. For example, social co-branding and joint planning can strengthen and amplify efforts while continuously evaluating progress can help save valuable time and resources and identify opportunities for improvement.

With this conference, NCI encourages stakeholders to take up the gauntlet and work together to develop and test solutions to this issue. Discussions over the two days showed that many clinical trials stakeholders are eager and ready to accept this challenge.

References

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