NIH NATIONAL CANCER INSTITUTE

clinical trials & social media

At the Crossroads of Social Media and Clinical Trials

A Workshop Summary

U.S. Department of Health and Human Services | National Institutes of Health

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A Note From the Organizers

This workshop, At the Crossroads of Social Media and Clinical Trials, resulted from discussions within the National Cancer Institute's (NCI) Cancer Moonshot[SM] program in response to recommendations received from a Blue Ribbon Panel of experts convened by NCI (Cancer Moonshot[SM] website n.d.). The Blue Ribbon Panel highlighted direct engagement of patients in cancer research as an important priority for NCI as part of Cancer Moonshot's mission to accelerate progress in cancer research.

Patient contribution to cancer research is often in the form of participation in clinical trials. For many who have exhausted standard-of-care therapies, trials represent hope for benefiting from a treatment under investigation. Unfortunately, many cancer patients are unaware of clinical trial opportunities and many oncologists are uncomfortable raising clinical trial enrollment options with their patients. Moreover, clinical trials can seem complicated and the idea of experimental treatments can be daunting. This unique workshop was, to our knowledge, the first opportunity for multidisciplinary experts to unite around tackling these longstanding challenges through social media.

Approximately 70% of online adults in the United States are regularly on social media (Pew Research Center 2018) and many of those turn to the internet when searching for health information (Fox 2011). Social media is a powerful vehicle for connecting remote and dispersed communities (such as rural patients or patients with rare cancers) to clinical trials and other resources. Social media can also facilitate clinical trial engagement for traditionally marginalized patient communities, including minority populations. Given the large and diverse population online, the use of social media presents a powerful opportunity to bring the benefits of clinical trials to light.

Patient-advocates, clinicians, researchers, and social media leaders who attended the workshop expressed enthusiasm and appreciation for the opportunity to gather as a community on this important topic. Many in-person attendees commented on the value of these interactions in promoting new ideas as well as the need to continue promoting such gatherings. The online audience response was equally enthusiastic. Over 4,000 tweets from online and in-person attendees reached a worldwide audience. Some of the top recurring themes at the conference were: (1) the quintessential role of patients as partners in trials and the need to incorporate their input into trial design, (2) the need to share more study results with the community, and (3) the need for more regulatory guidance on the use of social media in interacting with the community and potential trial participants.

We thank all of those who joined us for the event and those who continue to carry this conversation forward into action. We invite you to explore the following workshop summary and join in on the conversation at #ClinicaltrialsSM.

Sincerely,

The NCI Clinical Trials and Social Media workshop planning team

Introduction

On June 7–8, 2018, nearly 170 clinicians, researchers, health care providers, patient-advocates, and cancer survivors gathered at the Ruth L. Kirschstein Auditorium at the Natcher Conference Center on the National Institutes of Health (NIH) campus, with an additional 990 people watching via webcast, to exchange knowledge and synthesize new ideas for improving education and awareness about cancer clinical trials in the community through social media. The conference was sponsored by NCI and the Cancer Moonshot Network for Direct Patient Engagement Implementation Team.

The workshop provided a highly interactive setting for stakeholders to build on the work that NCI and the clinical trials community are doing to engage and educate the public and health care providers about cancer clinical trials. Diverse stakeholders met to exchange information and discuss how to work together to improve education and informed decision-making about clinical trials participation through the use of social media.

The workshop consisted of six sessions and five breakout discussions. The sessions were:

1. Clinical Trials Go Social—Connecting Trials to the Community
2. Engaging Patient Communities Online
3. Clinician Focus—Community Building and Outreach
4. Innovation Through Collaboration and Partnership
5. Social Media Tools and Metrics
6. Future Considerations

Jeff Abrams, M.D., associate director of the Cancer Therapy Evaluation Program at NCI, set the tone of the workshop during his welcome presentation. Abrams noted that one goal of the workshop is to "collectively realize the usefulness of social media" by fostering greater uptake of digital communication platforms and strategies to support NCI's clinical trial arena. He also said that successful engagement with the patient community will help stakeholders share information more quickly with prospective and current patients and clinicians.

Providing a demonstration of the power of information sharing through social media, Abrams referenced the Trial Assigning Individualized Options for Treatment (Rx) (TAILORx) trial, a groundbreaking breast cancer trial with more than 10,000 women participating over a 12-year period. The trial found that most women with a common form of early-stage breast cancer do not need chemotherapy after surgery.

Upon release of the results in the *New England Journal of Medicine* and at the American Society of Clinical Oncology annual conference, results spread worldwide through Instagram, Twitter, and blog posts, demonstrating the power of information dissemination through social media. Abrams said he hoped this broad dissemination of the trial results would help lead to their adoption into routine practice and guide clinicians and women in their breast cancer treatment decisions. Abrams pointed out that as cancer treatments evolve to treat smaller, more molecularly defined subsets of cancer, social media can help us tailor our messages to engage diverse communities. In closing, he tasked attendees to think collectively on how best to realize the potential of social media to speed enrollment into clinical trials.

Social Media—A Platform for Hope

In her keynote presentation, ***Susannah Fox***, former chief technology officer for the US Department of Health and Human Services, called social media "a platform for hope." She said there was an "ethical obligation" for the clinical trial community to understand social media and to act in an ethical way by matching patients with researchers for "conversations," by sharing information at global speed through the internet. It is disappointing, Fox asserted, how late clinical trial stakeholders—including researchers, clinicians, doctors, and scientists—are joining the social media conversation. She urged them to catch up to patients and patient advocates in discovering how social media can affect clinical trials. She described clinical trials as currently a "product few want to buy" and said that "people are not buying what researchers are selling."

Fox noted that many clinical trials researchers were trained before the advent of social media. They "need to be convinced that social media is essential to their work."

To illustrate the power or reach of the internet and social networks, Fox referenced statistics and data from the Pew Research Center and noted trends in internet access, mobile access, and social platforms.
In 1996, 14% of adults had internet access; in 2018, 89% of adults had access. There has been a cultural shift, with people now expecting to have on-demand access to information at any point and time. This shift also applies to older adults, one of the harder-to-reach populations for clinical trials: 82% of adults ages 65–69 and 75% of those ages 70–74 use the internet. For those who are age 80 and above, 44% use the internet.

Not surprisingly, she noted, older adults with a college education and those living in higher-income households are significantly more likely to use the internet than those with less education and less wealth. Ninety-two percent of older adults with college degrees have access to the internet, compared to 49% of older adults with a high school diploma. But Fox was quick to caution attendees not to ignore the offline older adults; their caregivers and family are highly likely to go online for health information.

Fox also noted that 9 out of 10 adults have mobile access, with 80% of adults over 65 using cell phones and 42% of those over 65 using smartphones. Referencing social media platforms, Fox said that 7 out of 10 adults have a profile online (e.g., Facebook, Twitter, Instagram). This number is higher among teenagers.

These trends have "cracked open the flow of information," Fox said. She explained that the internet has facilitated the flow of information from trials researchers and clinicians down to patients at a faster speed. But information also needs to flow up from patients to clinicians and scientists—this is where we often see resistance from clinicians and scientists. The stumbling block is not access to information, but access to each other, Fox noted. Clinicians and scientists need to be enticed and convinced that they will learn from patients and their families as much as patients will learn from them.

"We must do a better job of listening to people who use [social media] tools," Fox said. Social media can allow people to hear what is happening in clinical trials. It's not hard to get patients to participate in clinical trials when their curiosities and needs are respected, she added.

In a particularly emotional moment, Fox described how her father was diagnosed with stage IV melanoma in 2016. Unfortunately, shortly after infusions started, he had numerous side effects, which led him to stop the trial early. He "washed out" of the trials, said Fox. As she explained, the term "washed out" captures how her family felt. Like a wave had come over their boat and washed her father over the side and out to sea. They also felt very alone because they never heard from those researchers again.

According to Fox, if there were Yelp ratings for clinical trials, she would have rated her father's trial with one star. Maybe trials should be rated, she suggested.

In response to Fox suggesting that researchers listen to patient discussion for a better understanding of patients' experiences, an attendee expressed concern that it is not ethical to "listen where you're not wanted." Fox suggested finding models that invite clinicians to share in discussions and that make it clear they are listening. For example, on SmartPatients.com, a platform that facilitates patient participation in clinical trials, there are separate forums for clinicians and patients. Forum moderators search the forums for patient comments that might be interesting to clinicians and will ask forum members' permission if moderators see a post they would like to share with clinicians.

Connecting Trials to the Community

Session chair ***Andrea Denicoff, RN***, head of operations for NCI's National Clinical Trials Network (NCTN), spoke about the challenges of accruing patients for cancer trials and how social media could help. Her hope was that social media could be better leveraged as a tool to inform and educate patients and ultimately encourage more people to consider participating in clinical trials.

Denicoff provided attendees with information on historical accrual challenges, such as lack of community engagement around clinical trials, lack of interest in trials, lack of awareness of clinical trials as an option, and failure of doctors to recommend trials to patients.

The issue becomes, she said, to understand the role of social media and determine whether it can help increase patients' awareness of trials, encourage doctors to recommend trials, and improve researchers' communication skills to enhance public understanding about their studies.

Denicoff pointed out that the Cancer Therapy Evaluation Program created a Twitter account earlier this year to provide NCI grantees and sites with more information about clinical trials and to help educate audiences on clinical trials.

Denicoff identified the following questions that providers and sites should ask themselves when communicating online:

- What is the goal of using social media?
- How can it be used as a tool to help us?
- Who is the right target audience?
- What types of social media should be used?
- How is success measured?

Wendy Lawton, communications and public relations manager for SWOG (formerly the Southwest Oncology Group), suggested during her presentation that some of the problems in recruiting clinical trial participants are competition and confusion.

The sheer number of global trials has exploded. Lawton cited ClinicalTrials.gov statistics showing that in 2003, 8,588 trials were listed on ClinicalTrials.gov. In June 2018, that number had grown to 274,183. At the same time, trial language is confusing, filled with scientific terms and drug names that can be difficult for people to understand. Additionally, important information is not always prominently displayed, such as who to contact

for more information. Lawton compared online cancer trials to "looking at a 38-page menu written in French, and when you try to order, there is no waiter in sight."

To ease confusion and increase participation in NCI trials, she suggested:

- Promoting high-priority NCTN and NCI Community Oncology Research Program trials together
- Taking a stance of educating about trials—not selling them
- Showing NCTN value and impact to the public
- Using plain language in all online venues
- Creating patient-centered websites and online search tools
- Providing exceptional customer service, possibly through an expanded NCI Contact Center

Where Are the Researchers?

In his presentation, ***Mike Fisch, M.D.***, director of medical oncology at AIM Specialty Health, took the question of how to use social media to increase education and engagement in trials and applied it to rallying oncologists to use social media, cautioning that it has not been so easy to get oncologists to embrace social media. Fisch indicated that Twitter is the major platform that doctors use to engage the public and each other.

According to Fisch, oncologists use Twitter for the following reasons:

- Find information
- Amplify good information
- Be found and seen
- Actively create tweets to share information
- Actively engage with others

But it has been a slow process. In 2011, when Twitter use was at about 50% of what it is today, Fisch first saw the potential of this network to affect clinical trials by increasing community participation. At that time, however, researchers expressed concerns regarding the lack of guidance from government agencies, and the potential for descriptions of ongoing clinical trials to be considered inducement to research.

To move forward and encourage more scientists, researchers, and physicians to use social media, Fisch suggested the following strategies:

- Increase local institutional encouragement and support
- Use local mentors to guide the clinical trial community
- Use a "crawl, walk, run" attempt by teaching oncologists to extract information from Twitter without having to tweet or sign up for a Twitter account

In addition to the reluctance of some trials researchers to participate in social media, there are also ethical considerations. Instead of ignoring social media, use it ethically, said ***Luke Gelinas, Ph.D.***, chairperson at Advarra Institutional Review Board (IRB) and senior advisor at the Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard. Even though many IRBs express apprehension, there is "no putting social media back in the box."

There is an obligation, Gelinas claimed, to alleviate under-enrollment and increase participation rates. He noted that social media has been leveraged across various research areas with success, particularly among historically hard-to-reach populations, for example, gay Latinos and young cancer survivors.

"Does social media raise new ethical questions?" he asked. He answered that it depends. Gelinas suggested determining whether social media should be considered passive recruitment or active recruitment to help guide what may or may not be appropriate. He described passive recruitment as distributing materials at a general location to attract patients, such as hanging an ad in a clinic or other public space. Active recruitment, on the other hand, involves approaching and interacting directly with potential patients. Posting an ad on Facebook could be like hanging an ad in a clinic. Likewise, tweeting an ad is like hanging it in a public space. These activities could be considered passive recruitment and may not raise any ethical considerations. However, noted Gelinas, approaching a patient in a Facebook forum is like approaching a patient in a hospital. This may raise concerns about sharing personal identifying information and whether consent is voluntary.

There are privacy risks inherent in social media. He likened it to a company collecting data and selling it to a third party; although, Gelinas noted, individuals can manage their privacy settings to help guard against the release of sensitive health information.

Gelinas suggested that individuals who use social media platforms accept the risks involved. For example, patients posting to a public page accept the risk that information they post will be public. Building on Fox's theme, he said researchers have an obligation to mitigate risks for patients and not amplify them. If a clinician is trying to recruit patients from an open Facebook page, Gelinas suggested that the clinician tell potential patients not to post to the forum but to call or send a private message.

Another example involves a researcher seeing a tweet looking for clinical trials on depression. Can the researcher tweet back information on a trial? Tweets are public and could call attention to sensitive health information, thereby amplifying privacy risks. Instead, Gelinas advised using Twitter's private message function.

Online communications between trial participants also pose privacy risks. There is the potential of unblinding a clinical study when patients describe their experiences, and it can undermine the understanding of the study, which can affect ongoing consent. To mitigate these risks, Gelinas suggested:

- Asking participants not to discuss their treatment on social media during the trial
- Disabling comments
- Actively monitoring the discussions
- Educating participants about the risks of social media

One attendee questioned whether there was an ethical issue with promoting clinical trials as viable treatment options. But Gelinas did not see promotion of trials on social media as presenting more ethical issues than traditional trial promotion. He explained that the language in the scripts used upon first contact with potential study subjects is carefully crafted, and the same standards should apply to social media. Regarding IRB approval, he suggested finding a middle ground: use a basic script and give the IRB a list of likely questions and proposed responses.

Don Dizon, M.D., director of women's cancers at Lifespan Cancer Institute and director of medical oncology at Rhode Island Hospital, spoke on the importance of community building and outreach by clinicians. He agreed with Fisch that calling colleagues to the social media table has been neither easy nor effective. One survey showed that many clinicians never or rarely go on social media. Sixty percent of clinicians who responded to the survey did not see it as worthwhile but did see value for patients.

According to Dizon, clinicians see social media as a waste of time and a huge risk with unknown reward, they do not see the academic merit of it, and they consider it work. He suggested engaging clinician peers by providing evidence of the benefits of using social media.

SWOG, of which Dizon is chair of the Digital Engagement Committee, has incorporated digital engagement into its array of communications channels. SWOG has defined digital engagement as any tool that allows for two-way interaction. The mission of the SWOG Digital Engagement Committee is to enhance communication with the community, improve connections between SWOG and the public, and improve the research enterprise. The committee will be reviewing their communications that have a digital tool as both a primary or secondary objective and determining if the objectives are well delineated, the methodology is sound, what the analytic plan looks like, and whether there's merit.

Dizon is part of the Collaboration for Outcomes Using Social Media in Oncology. The collaboration's efforts focus on clinical collaboration, defining best practices, and conducting outcomes research and empiric research to establish or refute the benefits of social media. So far, the group has promoted hashtags online, published several articles, and started qualitative research. Dizon stressed that this work is necessary because patients are going to take the information they get online to their clinicians. If the clinician doesn't know where the patient got the information, they are not starting at a fair point to discuss it, he noted.

Engaging Patient Communities Online

An emotionally moving session on communicating with patients online resonated with Fox's earlier comment about social media serving as a platform of hope. Patient-advocates, family members, and survivors spoke about how patients are using social media for support after a diagnosis and the impacts on their lives.

Janet Freeman-Daily, M.S., cofounder of the ROS1ders, an online cancer patient community, is a cancer survivor, and stated emphatically that the information she found on social media saved her life. After being diagnosed with a rare form of lung cancer that alters the *ROS1* gene and becoming frustrated with the lack of information about genomic testing and clinical trials online, Freeman-Daily expanded her search to find out all she could. In a patient forum on social media she learned about a clinical trial that she was eligible for. She participated in the trial and now has no evidence of the disease. To her and other patients, clinical trials are "not just research"—they are hope.

As Freeman noted, patients online can find many support resources including blogs, community platforms, Facebook communities, and Twitter hashtag communities. These can offer hope, support, education, empowerment, and connections with other patients. Patients can use these platforms to feel less alone and have frank conversations with others about information their family members may not want to hear.

Social media platforms also "allow patients to become part of the team," Freeman-Daily said. Patients don't want to be the medical experts, they want to *partner* with experts, she added. Scientists and researchers should take advantage of the knowledge patients bring.

Freeman-Daily explained how online cancer communities also drive innovation through:

- Patient education and outreach
- Research initiated by patients
- Patient-partnered research (e.g., researchers start a project but bring in patients early on to discuss what is important to study)
- Research driven by needs of patients

Online communities can provide real-world data, which is especially useful in rare cohorts. For example, the *ROS1* mutation occurs in only 1% of lung cancer patients, and only 35 new patients are eligible for trials each year. Despite this fact, there are more than 200 patients represented in the ROS1ders.

Freeman-Daily described ways trials researchers could consider the use of social media in clinical trials:

- Include patients in the beginning when designing the clinical trial.
- Remove some barriers to pharmacy communications with patient groups.
- Share preclinical data and trial enrollment status freely, since patients are going to share this information anyway.
- Establish ethics guidelines for patient-researcher partnerships.
- Train patients and advocates in the "science" of a given trial so they can be more knowledgeable.
- Create connected communities for enrolled patients to enable facilitated discussions with other patients.

Gilles Frydman, whose wife had cancer, founded Smart Patients, a system of online cancer communities for patients and families. He urged researchers to put a human face to clinical trials to bring public understanding of the real people behind trials.

Frydman described three examples of dehumanization in medicine:

- Impaired agency of patients—patients don't see role models or people who look like them for active engagement, especially minority patients. For example, he highlighted a Google search on "patients" that brought up images of white people who look sick and are in hospitals.
- Deindividuation—a Google search on "clinical trials" does not bring up any images of real people.
- Dissimilarity of roles—a Google search on "clinical trial patient" shows individuals under the control of doctors.

This dehumanization is one of the main reasons why there is a lack of accrual in clinical trials, he claimed. Patients need to be complete partners in trials, not the subjects of clinical trials. People need to see that trials are a human endeavor with real people behind the process—scientists, trials researchers, and patient participants.

Frydman highlighted his current work with One Person Closer, a project working to address the need for humanization of trials. One Person Closer shows stories of clinical trials online, including pictures of patients, scientists, and physicians. Frydman presented three stories of important historical medical discoveries

showing portraits of the scientists, clinical researchers, and patients who were all connected to the discovery and eventual introduction of drugs such as Gleevec, the first successful targeted therapy, into the clinic.

Frydman pointed out that stakeholders need to change completely the way they communicate about science and clinical trials. To put the issue in perspective, he compared the 5 billion views on the YouTube video for the song Despacito in 16 months to the 7,500 views of CNN's video on clinical trials in four years.

Social media can play a major role in recruiting patients, said ***Jamie Holloway, Ph.D.***, a clinical research advocate for Science 37, a company that focuses on the development of networked patient-centric models for clinical research. She surveyed Twitter users about barriers to participating in clinical trials, with the biggest barrier being finding relevant trials (more than 70%). Another major barrier was eligibility criteria being too strict (70%). Most other barriers involved geographical and time limitations (e.g., taking time off from work and traveling).

Science 37 conducts decentralized clinical trials to address geographical and time limitations on patients. Holloway noted that it has done a good job of using social media effectively to help move clinical trials away from hospitals and clinical settings. Patient recruiting is done primarily through Facebook and Instagram ads, and all consent is received online. Any eligibility requirements are satisfied at a local medical facility or home health service. Once a patient is enrolled, they receive the drug and anything they need for the trial in the mail. For example, the AOBiome study was the first study that was completely site-less from start to finish. Patients were recruited through social media ads. More importantly, said Holloway, minority participation in the study was high at 41%, which is "pretty much unheard of."

Holloway built on what other speakers had said about implicit bias. While most of the reasons why doctors don't offer patients information about trials are altruistic (e.g., they try to be considerate of patients' needs and concerns and don't offer trials they perceive as not fitting the patients' family or monetary circumstances), this lack of information can also prevent minority patients and patients from underserved communities from being offered clinical trials. Research has shown that "patients from minority populations just aren't offered clinical trials at the same rate as their Caucasian counterparts." If a person doesn't know a trial exists, they can't participate in it. If a doctor doesn't tell them about it, they don't have the option. This provides an excellent opportunity for social media to address that need, Holloway claimed. Ads placed on social media platforms can be searched based on keywords and can be found online regardless of a patient's skin color or where they live, she explained. Any patient searching will have the same ad or site pop up, and they will make the decision for themselves.

Holloway admitted that decentralized models wouldn't work for every clinical trial. But she noted that some features of the decentralized model could be applied to fixed-site trials:

- Reduce barriers to geographic limitations:
    - Group procedures and tests to limit the number of in-person visits
    - Limit procedures to those that are necessary
    - Consider some off-site procedures (e.g., blood draw done at local lab and shipped to clinic lab)
    - Consider compensation for travel expenses and individual time
- Use targeted social media outreach:
    - Make web presence easy to find
- Continue to engage patients even after trial ends

Innovative Uses of Social Media to Raise Awareness

Partner Up

Lakshmi Grama, M.A., M.L.S., associate director in the Office of Dissemination and Digital Communications at NCI, chaired a session on the importance of collaborations and partnerships to expand reach. She said NCI's communications mission is also aligned with NCI's efforts related to clinical trials, and it is focused on improving awareness and knowledge of these trials.

"Social media is an extension of [NCI's] dissemination mission." It helps NCI engage with new audiences, have two-way conversations, connect communities to useful content, and cultivate audiences and build trust.

NCI has used social media events on Facebook and Twitter to leverage its audience, said Grama, with 80 to 100 people viewing events live and 6,000 to 8,000 people viewing them within 30 days.

Social media events can be used to:

- Bring experts directly into conversations with patients
- Focus on cancer topics that are of interest to the community
- Integrate clinical trials as part of treatment options
- Align with cancer observation months to build ongoing conversations

She stressed the importance of understanding the various social platforms to use them as effectively as possible. For example, she explained that social media sites are owned by private entities and driven by algorithms that share content based upon what the algorithms think would be interesting to its audiences.

Additionally, Grama noted that each social platform is different. For NCI, "what works on Twitter doesn't work on Facebook." NCI's audience on Twitter is more connected to the issues and topics around cancer, while on Facebook the audience consists of those who have been personally touched by cancer and are not necessarily plugged into the social networks surrounding cancer.

NCI's Facebook live events are effective platforms for engaging with patients and caregivers who are not necessarily plugged into cancer support networks. They enable better interaction, and people can ask questions, she explained. NCI also uses the video after the event to increase impact.

Twitter chats are a challenge for NCI, particularly since NCI's engagement on Twitter is episodic and intermittent. On the other hand, Twitter is good for ongoing conversations within a connected community, Grama said. For example, the breast cancer and lung cancer communities have regular "chats," either weekly or monthly. They are successful because they have built a community that knows it will find value in engagement.

Regardless of what type of event is held, Grama stressed that "partnerships are critical." NCI events with partners are more successful than those without, she claimed. NCI recently partnered with cancer centers, advocates, and patient networks for its events and found that combining audiences increases reach. "There is a need for trusted voices that are comfortable interacting with the public," she said.

NCI is constantly looking for partners to work with, and Grama would love to see campaigns around clinical trials, like the Memorial Sloan Kettering Cancer Center childhood cancer campaign that happened in partnership with Brandon Stanton from Humans of New York, a photography and story project that provides a glimpse of the daily lives of people on the streets of New York City.

She expanded on this idea in response to a question from an attendee about the number of campaigns out there and whether the clinical trial community needs a new one. Grama acknowledged that there have been many campaigns but said that in the past they were "organization-driven." Social media has changed the nature of campaigns, and the more successful ones are community-driven. Researchers, clinicians, and communicators need to change the way they plan and execute campaigns. Co-creating campaigns with the community in a way that effectively tells stories and connects and resonates with audiences at an emotional level might be a way to leverage the power of social media, suggested Grama.

Yasmin Kloth, M.S., senior digital communications strategist at NIH, manages the All of Us social media program, which is part of NIH's Precision Medicine Initiative. Its goal is to enroll more than 1 million volunteers of diverse backgrounds to share their health information to build a data resource that researchers can use to better understand health and disease.

The engagement team at All of Us has been very successful in using social media to spread awareness of the program and recruit participants. For example, All of Us has built platforms on Facebook and Twitter. Using the hashtag #JoinAllofUs, on May 6, 2018, NIH distributed a suite of materials developed for the campaign to individuals and groups who are deeply connected with diverse communities to promote the launch of the program in a grassroots manner and break down silos. Within 24 hours of the launch, the program had reached 50 million people; and since launch, Facebook Live events have reached more than 100,000 people. What is exciting to Kloth is how people are connected on these digital spaces. Pointing to a chart visualizing web of connected All of Us networks, she noted how those on the periphery have helped the message spread even further. She added that this was a demonstration of the power of leveraging networks.

Echoing Grama, Kloth stressed the importance of partnerships to reach beyond the immediate community one normally interfaces with. For example, All of Us held two Twitter chats after launch, one with the NIH Twitter handle and one with WebMD. The NIH event reached primarily a government audience, while the one with WebMD had a smaller government audience, a larger doctor audience, and an advocacy audience. She also pointed out that the connection between online and offline partnerships was essential to help organizations meet people where they are.

Elizabeth Buchanan, Ph.D., director of the Center for Applied Ethics at the University of Wisconsin, spoke about the changing relationships between clinical researchers, trials participants, ethics boards, and the public. She gave a brief history of the emergence of patient support groups in the early 1990s and the explosion of cancer support networks on social media in 2000. For example, in 2005 there were 400,000 internet cancer support groups. She added that today, according to Facebook, there are "more cancer support pages on Facebook than any other health or disease issue."

Big data emerged in 2010 and now runs social media. These technologies are now being used for research. IRBs are working to develop guidelines, she noted, and have made a lot of progress in trying to codify principles. Buchanan mentioned several groups working to develop best practices and ethics guidelines in social media research.

Buchanan noted many of the ethical concerns IRBs have about using social medial tools:

- Privacy and security
- Receiving explicit consent from participants
- Misinformation
- Unblinding patients and trials
- Nonconsensual access to data
- Patients sharing adverse effects information during a trial

The bottom line, she claimed, is that patients are humans and are not going to change, so researchers must change. While stakeholders need to be aware of these privacy issues, Buchanan urged researchers to be brave. IRBs are retooling, retraining, and learning; they need to hear from the research community and patient advocates to better understand what is appropriate and what is not. In giving her final thoughts, Buchanan noted that more patient advocates should be on IRBs. She also urged researchers to think about the extra time that goes into social media research.

David Charles, M.D., chief medical officer at Vanderbilt Neuroscience Institute and a leader of the Coalition on Clinical Trials Awareness (CCTA), shared information about the coalition's main message—if the public is educated on the benefits of clinical trials, they are more likely to consider participating in one. The group, which consists of more than 50 organizations, holds an annual Clinical Trials Awareness Week. At last year's event, the group came away with four key points:

- Support patients navigating the clinical trials landscape
- Empower physicians to talk about clinical trials with patients
- Engage diverse stakeholders
- Relay the benefits of clinical trials to society

Charles went on to talk about how successful public awareness campaigns, such as one for organ donation that led to most states allowing people to select organ donation on their driver's license, can help raise awareness of clinical trials. He noted that a survey by CCTA found that 40% of surveyed adults did not understand clinical trials and that 32% of the public indicated they would consider participating in clinical trials with a better understanding of what they are. He added that the purpose of a campaign would be to simply elevate the public's understanding of the benefits of trials to society.

During the 2018 Clinical Trials Awareness Week, CCTA and participants used the hashtag #CTAW2018, which garnered 8.413 million impressions on Twitter and more than 1,400 tweets. The coalition envisions a public-private partnership for a future campaign—a campaign funded largely privately in partnership with the public.

Charles posed a very intriguing question to the audience: should informing patients about clinical trials become standard of care? In his opinion, the answer is yes.

Boot Camp Translation

Suzanne Millward, M.P.H., engagement methods coordinator for the University of Colorado's Data Science to Patient Value (D2V) Initiative, began by discussing some main points that arose during a symposium she and colleagues hosted about using virtual platforms (including social media) to engage stakeholders in health care research. Some of the discussion points that resulted from the symposium included:

- Low comfort levels among health care researchers using social media for research purposes, despite the many opportunities and efficiencies provided by social media
- Increased importance of transparency in research conducted via social media
- Need for better standards in the virtual research arena to address privacy, regulation, and standards of reporting
- Question of whether virtual platforms can replace in-person engagement
- Need to ask stakeholders whether they want to be engaged virtually or in person
- Extent to which virtual platforms can break down preexisting hierarchies
- Question of which populations may not be able to participate in virtually-conducted research
- Need for more rigorous process and outcome measures in the virtual realm
- Ethical considerations in virtual engagement that are presently surfacing

Millward then went on to provide details of a method of community engagement through which community members may eventually create materials for use on social media platforms.

Boot Camp Translation (BCT) was developed by the High Plains Research Network and their Community Advisory Council in Colorado (Zittleman et al. 2009). BCT is a program that facilitates bidirectional engagement of community members, researchers, and medical professionals to brainstorm ways to translate medical information and guidelines into understandable messages and materials for dissemination into the community. BCT is a "robust process of engagement that has been rigorously tested and shown to work," Millward claimed.

Millward stressed that BCT participants are not research subjects—"they're partners." This means during the BCT process IRB approval is not needed. But, she cautioned, once materials are developed, IRB approval is needed. The process involves:

- Six to 12 months of in-person meetings between community members and medical professionals
- One full-day session that includes a presentation to the group by a medical expert and an afternoon discussion among the community partners
- Thirty-minute focused phone meetings every few weeks
- A few two- to four-hour in-person meetings over the engagement period

Millward provided examples of BCT products created by the High Plains Research Network to increase colorectal cancer screening in rural Colorado. These materials included a farm auction flyer, a mug with "Got Polyps?" on it, and a flyer with a local businessman on it and the text "Testing is worth it" (Boot Camp Translation website n.d.). More than 65% of people surveyed in the community saw at least one of these items, and testing for colorectal cancer in the community increased (Zittleman et al. 2009). Millward noted that she had not been part of this study team, but that these materials were some of her favorite examples of products that can arise through the BCT process.

Social License

Sally Okun, RN, B.S.N., vice president of policy and ethics at PatientsLikeMe and keynote speaker, introduced the concept of "social license"—a form of acceptance or approval that is earned and maintained by those demonstrating trustworthy behavior. While generally earned from a community by an external stakeholder, Okun suggested that social license be mutually earned by researchers and social media participants to ensure reciprocal trustworthiness.

The components of social license to which both researchers and social medial participants should aspire are:

- Legitimacy—creative engagement among the researchers, sponsors, and social media environment must ensure information about each other can be easily shared and questions sufficiently answered.
- Credibility—researchers and those within the social media environment must consistently provide true and clear information about each other's community and comply with commitments made to the respective community.
- Trust—researchers and social media participants must be willing to learn from each other and acknowledge mutually acceptable areas of vulnerability.

Okun explained key elements needed for researchers and social media participants to mutually earn social license from each other:

- Transparency and intent—openness to divergent views. For example, what does social media need from researchers, and what do researchers need from social media to achieve outcomes of mutual interest?
- Integrity and fairness—ensure that "smaller" voices from both the research community and social media are heard. Be authentic and human in relationships as they evolve and mature.
- Consent—should be informed and understood and rely on transparency and fairness (i.e., use data for permitted uses; don't use information in unintended ways).

She provided the example of PatientsLikeMe to show how social license is earned from a community with mutual interests. PatientsLikeMe is an open, online patient-facing research-based community built within a social network model. It began in 2004 for amyotrophic lateral sclerosis (ALS) patients, but in 2011 was expanded to include any condition. Today there are more than 630,000 members with more than 2,700 diseases, and 4 million forum posts. Okun demonstrated the value of earning social license within a patient network such as PatientsLikeMe by citing a case study from 2008 seeking to investigate the effects of lithium in ALS reported in a small Italian study. More than 160 patients were tracking their own outcomes on home-grown spreadsheets and asked PatientsLikeMe to assist them by creating tools for systematic data collection. When PatientsLikeMe analyzed the data, it appeared that lithium did not impact progression of ALS. Two subsequent NIH studies found the same results. Okun pointed out that the ability to gather preliminary data from communities such as PatientsLikeMe could have saved millions of NIH dollars. Interestingly, a 2017 meta-analysis of multiple ALS studies with genomic data showed lithium may have slowed the progression of ALS in patients with specific genetic variants (Ruben et al. 2017). Hence, there is obviously a need to continue research, and PatientsLikeMe will collaborate with others to conduct further studies. This commitment to continuous and shared learning from patients and from science demonstrates how PatientsLikeMe earns the requisite credibility, legitimacy, and trustworthiness of social license from both communities, Okun claimed.

Okun stressed that PatientsLikeMe treats patients as partners. People are gathering data on their own, and researchers, clinicians, and other entities may learn something new from them. Through its reaction to the lithium study, PatientsLikeMe earned social license from community members, she said.

Importantly, Okun suggested that in the digital age, the clinical trials community may need a new social contract. She recommended that stakeholders from both research and social media communities do the following:

- Share information and knowledge with each other's communities.

- Try to understand the similarities and differences that may characterize clinical trial settings and social media communities (e.g., representativeness and motivation to participate).
- Show that the clinical trial community and social media community are made up of real people.
- Understand the regulatory requirements in the clinical trial community.
- Be transparent about potential issues surrounding participants (e.g., unblinding and privacy issues).

Okun elaborated on PatientsLikeMe's use of patient-informed principles for designing patient-centric user experience and measurement tools. Patients provide ongoing feedback about their clinical trial experiences and offer valuable insights for improving the full spectrum of clinical trials from design to ensuring that research findings are returned to participants.

Crafting the Right Social Media Message and Measuring Success

Several presenters discussed how to know whether a given social media strategy is effective as a tool to raise awareness of clinical trials.

During her presentation on social media tools and metrics, session Chair ***Holly Massett, Ph.D.***, senior behavioral science analyst for the Cancer Therapy Evaluation Program at NCI, spoke about viewing engagement as a metric to assess the impact of social media on its users. The "social media messages must engage the audience," she explained. Messages need to be interesting, personally relevant, motivating, believable, and credible, elaborated Massett.

She described social marketing research where NCI conducted focus groups with patients and caregivers around clinical trial awareness and interest (Massett et al. 2017). Her group learned that people were more likely to consider a clinical trial when trials are "normalized," that is, trials are shown as one possible treatment option available to patients like them. Massett suggested that messages 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" in a realistic manner that does not over-promise
- Focus on clinical trials as state-of-the-art versus cutting-edge technology
- Avoid showing trial participants as "heroes" who take great risks that others might not
- Point to clear, direct actions people can take with respect to finding a trial
- Clearly identify the sponsor who is conducting the trial

Based on the focus group findings, Massett's team developed a series of ads for clinical trials and tested their impact on participants' interest in clinical trials. All groups significantly increased their likelihood to consider a clinical trial in the future after seeing the ads (from their pre-ad score); and whereas 36% said they were likely to consider a clinical trial before seeing the ads, 64% said they were likely after viewing the ads. Massett reiterated that clear and acceptable messages have the potential to effect positive change and informed choice around clinical trials.

Jessica Schindelar, M.P.H., social media team lead for the Centers for Disease Control and Prevention (CDC), spoke about crafting the right message, for the right audience, at the right time. The four key steps to crafting a successful message, she explained, are strategy, effective content, engagement, and evaluation.

To develop a strategy, you must focus on what success means for you. Schindelar suggested asking the following questions:

- Who is the audience?
- What is the goal of the campaign?
- Where can social media support efforts?
- What resources already exist?
- What social media tactics are planned?
- What does success look like?

She said that each social media tool is different, reaching different audiences with different traffic. For example, Facebook reaches people primarily through engagement and has 2.2 billion monthly active users, while Twitter has 336 million monthly active users and drives traffic to other websites through information sharing. With more than 1 billion monthly active users, Instagram can be leveraged for sharing great visuals; however, links are not clickable so cannot easily drive web traffic.

Schindelar explained how to develop effective content by considering how people are seeing the information. For example, she noted that 94% of CDC's Facebook users access the platform through mobile devices.

Other tips for success include the following:

- Think mobile first. Most people use social media on mobile devices.
- Use language your audience uses.
- Be engaging. You have one second to catch your audience's attention.
- Provide value to people.
- Post regularly, when the target audience is online.
- Engage with your community.
- Use hashtags to identify keywords or topics of interest to make it easier for people to find your post.
- Use @ mentions and tagging to broaden reach.
- Avoid multiple calls to action.
- Be aware of changes to the social platforms you are using.
- Learn from your successes and failures.

Josh DeLung, M.A., strategy and quality lead at ICF, told attendees that to measure the success of a social media campaign, it needs to be evaluated and measured before, during, and after.

Before starting a campaign, goals need to be defined and data sources need to be determined (e.g., Google Analytics, native analytics like Facebook or Twitter, or other third-party tools such as Hootsuite, Tailwind, Iconosquare, and others). Stakeholders also need to determine how often to report campaign results and what type of reporting to use—traditional (e.g., Word documents) or electronic reporting (e.g., dashboards).

During the campaign, outcomes should be measured continuously and early. For example, said DeLung, 75% of engagement on Facebook comes in the first three hours. He advised not to wait until the end of the month

to measure. This is also the time to listen, he said. Listening is useful for informing content strategy and seeing how people are reacting to content.

After a campaign is the time to develop a plan based on the data captured by the report developed in the "before" phase.

DeLung summarized the six key steps to social media metrics:

- Start planning early and develop key performance indicators mapped to goals
- Monitor metrics continuously
- Differentiate between types of metrics and what they will tell you
- Map metrics to goals
- Make reports useful for analyzing outcomes
- Conduct action plan based on data captured

Framing Your Message

Expanding on how to formulate messaging that works, ***Marisa Gerstein Pineau, Ph.D.***, a researcher at FrameWorks Institute, suggested that "everyone is your audience." While patients and potential trial participants are the primary audience, research has shown that family members, health care professionals, and community members are extremely influential in decisions to participate in clinical trials.

She explained the concept of framing, which is a set of choices about how information is presented, what you emphasize, how you explain it, and what you leave unsaid. Framing addresses problems that arise when experts say something that sounds completely reasonable to them, but members of the public hear something completely different based on automatic assumptions. *How* something is said matters. She noted that framing is a process and described a study where participants were given different messages to determine how each would affect their support for evidence-based addiction policies. Those messages using interdependence and ingenuity messages worked better than those messages using empathy. In fact, those hearing the empathy messages were much less likely to support the policy than those hearing no message. She continued, saying that messages must be tested to avoid spending resources on messages that don't work or that may be harmful to your goals.

A frame that works, noted Pineau, can change knowledge, attitudes, policies, and engagement. Important frame elements include:

- Tone
- Values
- Metaphors
- Explanatory chains
- Narrative

She used Lasswell's model of communication to explain framing as it applies to clinical trials ("Who says what, in which channel, to whom, with what effects"). *Who* refers to NCI or other influential entities, *what* refers to a well-framed explanation of clinical trials, the *channel* is social media, and *whom* refers to the public at large. Using a model of communication such as this can help to increase understanding and interest in clinical trials.

Addressing Disparities in Underserved Populations

During a session on community building and outreach, ***Jonca Bull, M.D.***, vice president of PPD Consulting and former assistant commissioner for minority health at the US Food and Drug Administration, talked about engaging the various social media tools to facilitate broader participation in clinical trials among demographic subgroups. She referenced a *New York Times* article, "In Cancer Trials, Minorities Face Extra Hurdles," (Grady 2016) claiming that minority participation is currently lacking in cancer trials. Bull noted, however, that another study showed very few differences in the willingness of minorities to participate in health studies when compared with non-Hispanic whites (Wendler et al. 2006), meaning that these hurdles can be overcome.

Greater diversity can be created, and it matters, claimed Bull. Inclusion of relevant populations in clinical trials is critical to improving the safety and efficacy profile of medical products for all. When considering diversity and demographics, Bull explained that the bottom-line question is whether the right patients are in the trial. First, she said, look at the disease indication and the data surrounding it. Then determine whether the data is generalizable, meaning there are no known population differences and it doesn't matter what groups are in a trial, versus when there are known population disparities (e.g., prostate and breast cancer seem to be cancers with known minority population disparities). "It is important that trials are designed to reflect these clinically relevant characteristics."

Unfortunately, minorities face extra hurdles when it comes to clinical trials, including lack of awareness, lack of access, and implicit bias. The Federal Drug Administration (FDA) Drug Trials Snapshots for oncology show that participation of African Americans in trials is extremely low. It also shows that the geriatric population is underrepresented in clinical trials even if cancers tend to occur in older age groups (FDA 2017a).

Online recruitment, she said, is less successful for minority populations for a variety of reasons. Social media can be a useful tool to connect diverse patients to sites—for example, patients who are physically unable get to a trial site—but participating in the clinical trial remains inaccessible to these patients. Bull noted that creating greater diversity will require the collaborative efforts of industry, health professionals, and patients.

Bull referenced an article about the possible benefits of using social media, such as tweets, to reach minority populations. The article posed a question as to whether clinicians have a duty to tweet to overcome some of these disparities. However, she noted there are issues around privacy that must be considered.

Bull presented a series of videos created by FDA, featuring minorities to raise awareness of clinical trials and minority populations (FDA 2017b). She concluded her presentation by saying, "It is important to have someone that looks like that community" to help deliver these messages.

Nathaly Gonzalez, bilingual patient navigator and community outreach coordinator with the Capital Breast Cancer Center at Georgetown University, addressed the lack of minorities in breast cancer studies as she spoke about using social media to recruit Hispanic breast cancer patients. The Breast Cancer Center is conducting a genetic counseling study targeting Hispanics using Facebook, Google Voice text messages, and email to recruit patients. Flyers were first posted to Facebook in Spanish, describing the study, offering $30 gift cards to participants, and indicating whom to contact through phone or email. The center will then use Google Voice to provide more information to interested individuals. Gonzalez noted that when the study first started, she would call on average 10 individuals a day and only get two responses. Using Google Voice, she recruited 12 patients in the same timeframe.

Senior Citizens

Mina Sedrak, M.D., a geriatric oncologist at City of Hope, expanded on Bull's claims regarding the underrepresentation of the geriatric population. Sedrak described cancer as a disease associated with aging, with most cases occurring in those over 65 years of age. He explained that this population will continue to grow. In fact, in 2030 and above, "the largest segment of the population that will be growing are the patients who are 80 and above." There will be a surge of patients with cancer who are older adults. Between 2010 and 2030, that percentage and the number of patients with cancer who are 65 or older is expected to increase by 67%, he said. Unfortunately, there was little change in overall age distribution across NCI cooperative group phase 1 and phase 2 trials between 2001 and 2011, with participation of patients age 75 and older being a small fraction of patients. Sedrak also noted that older adults are underrepresented in FDA registration trials; this may be in part due to a lack of cancer research literature that includes older adults. Thus, doctors treating these patients don't have data on how best to provide treatment. This lack of evidence leads to under-treatment and overtreatment of this population and an increased risk of undue toxicity, claimed Sedrak.

Sedrak suggested that social media could be used to target:

- Patients, including elderly patients, to increase their awareness and knowledge of clinical trials
- Caregivers
- Physicians caring for older adults
- The public as a whole
- Researchers and policymakers to make effective changes in the availability of trials for older adults and eligibility criteria

There are data to suggest that older adults are online, as Fox noted in her keynote speech; however, Sedrak described challenges, including trust issues and transparency. With this vulnerable population, there is a fine line between advertising and coercion. When older adults are offered clinical trials, they want to participate, he claimed. However, due to implicit bias, doctors may be hesitant to offer trials to them to protect them from risk and out of respect for their possible interest in palliative care at the end of life. The solution, according to Sedrak, is for clinicians to consider the unique needs of the elderly patient when designing cancer treatments for them. Additionally, they need to widen the umbrella to encompass older populations when thinking of clinical trials. Sedrak presented a decision-tree diagram that could be used during the trial enrollment process to help include older patients. There is "a lot of value in raising awareness in how the elderly need to be involved in clinical trials," he stressed. "Older adults need a seat at the table."

LGBTQ Community

Erin Fordyce, M.S., M.Ed., a research methodologist at NORC at the University of Chicago, discussed issues surrounding trying to recruit lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) youth through social media. There are advantages and disadvantages to using social media to recruit hard-to-reach populations, she said.

Fordyce described a web survey that the university conducted with CDC on social media for the recruitment of gay males and transgender teens. Obviously, for this population, "we were not going to send a letter home" to a random sample asking if their child was gay, she explained. "Social media was our best option." They first developed ads targeted toward males, transgenders, or the general teen population. Some additional ads targeted black and Hispanic males. Gift cards were offered for completing surveys.

The ads were posted on Facebook, Instagram, Snapchat, and Google (text ad with key words). The goal of the pilot was to get 100 completed surveys within 30 days. They had more than 100 completed surveys in less than 24 hours, Fordyce said.

To determine the success of ads, one must consider looking at parameters other than the number of clicks, she warned, not just how many completed surveys there were. "You really need to look at the whole picture." For example, 51% of all respondents who started the survey came from a Snapchat ad, but only 18% of those respondents went on to complete the survey.

Fordyce explained that data quality will continue to be a primary concern and area of focus for future research. Concerns include respondents attempting to complete the survey just to receive a gift code, the use of fake email accounts to receive additional gift codes, and ad sharing. Further, if respondents complete the survey on multiple devices, technology aimed at preventing duplicate responses becomes irrelevant.

Social Media in Action

Metastatic Breast Cancer Project

Corrie Painter, Ph.D., associate director of operations and scientific outreach at the Broad Institute of MIT and Harvard, reiterated a common sentiment at the conference. Social media is a "place you find hope." The goal of using social media should be to generate a public database to understand what drives cancer, identify optimal treatments, and anticipate and preempt resistance, she said.

She described the Metastatic Breast Cancer Project, launched in 2015. It is a collaborative project between metastatic breast cancer patients, advocates, cancer researchers, clinicians, and clinical specialists, and all data is shared in the public domain. To date, more than 4,500 participants from all 50 states have joined due in large part to the patient grassroots "Count Me In" campaign amplified on Instagram. Painter demonstrated a graph showing that the most pronounced rises in enrollment could be traced back to Facebook and Twitter posts by advocates and other social media influencers. A similar study for prostate cancer patients is currently being developed.

Painter suggested that social media works particularly well with rare cancers. For example, angiosarcoma is a rare type of lung cancer, with 300 people per year diagnosed. The angiosarcoma "Count Me In" project currently has 315 participants enrolled since January 2018, noted Painter.

Painter urged clinicians to engage patients on social media throughout the length of the trial. "Go to the patients," she said, through existing patient and patient-advocacy communities. Be inclusive and think actively about diversity from the start. She also suggested working with patients before, during, and after a study. "Take feedback seriously," and show it. Patients will then see the changes, recognize their own voices, and see the difference they are making. "Authenticity is critical."

NCTN Presentations

Dispersed throughout presentations during the two days, individuals from NCI's National Clinical Trials Network (NCTN) described how its groups are using social media. NCTN, which consists of six groups that bring together researchers, investigators, patients, advocates, and federal partners, is leading NCI's efforts to use social media to enhance clinical trials.

Jamilah Owens, communications manager at the Alliance for Clinical Trials in Oncology, called social media "one of the primary shapers of national conversations on health care." It provides an opportunity to disseminate credible information, heighten awareness of clinical trials, and share information with other health professionals. The alliance has a formal social media policy that uses social media platforms (e.g., Facebook, Twitter, LinkedIn, and YouTube) to generate awareness of the alliance and NCTN, inform and educate about trials and the clinical trial process, enhance its accrual efforts, promote its mission, connect with members, track members, and connect with collaborators. For example, the Alliance for Clinical Trials in Oncology has 262 followers on Facebook, to whom it provides news, events, and trial results (e.g., Trial Tuesday, Cancer Awareness Days). On Twitter, it has 1,827 followers. Tweets highlight clinical trials and provide updates and trends (e.g., Throwback Thursday; retweets of American Society of Clinical Oncology, the American College of Radiology, and NCI). LinkedIn heightens the alliance's profile to 293 followers. On YouTube, the alliance uses private and public channels to host NCI and alliance trial videos and meeting presentations. The alliance posts new content on average five times a week. The group monitors and evaluates social media impact by looking at the number of impressions, page views, visits, shares, comments, retweets, favorites, and followers.

NRG Oncology is using social media as a tool to promote collaboration among the industry to improve clinical trials, according to ***Thomas George, M.D.***, a member of NRG's Patient Engagement Working Group. It uses social media to promote its mission by providing links from its Twitter and Facebook pages back to its website content and leveraging its diverse membership. George explained that the clinical trial information posted on NRG's website is limited to what the IRB approves. It's not patient-friendly and links back to ClinicalTrials.gov, he explained. The challenge is to move to a patient-centric approach with preapproved language that promotes education, awareness, and advocacy.

Lisa Callahan, communications leader for the Canadian Cancer Trials Group (CCTG), described how CCTG has integrated social media into its strategic communications plan. They use six separate digital media channels—Group Bulletin, Twitter, LinkedIn, Facebook, YouTube, and the CCTG website. Each channel is used for interaction, collaboration, content-sharing, and partnerships. The important thing, she said, is to pick the right channel to disseminate information. For example, CCTG uses Twitter to target all stakeholders and Facebook for patients and families.

Daniel Woods, operations manager for the Children's Oncology Group (COG) Foundation, noted that "COG historically has not had a significant social media presence. We started using Twitter only two months ago." But Woods does see this platform as likely becoming the "flagbearer with respect to our social media efforts." He praised the conference as being very informative and helpful to COG as it embraces social media more fully and described the social media COG is using. COG uses Facebook to highlight philanthropic partners and raise awareness of events they organize and highlight general news on significant developments. COG uses LinkedIn for recruitment efforts and to raise general awareness of its mission and research findings. Generally, COG doesn't experience accrual challenges, Woods noted, explaining why it has had a limited social media presence to date. It was not seen as a critical element of COG's communications strategy, he added. COG plans to start using social media to deploy resources that are currently on its website. While it was too early to measure the success of COG's social media use, Woods expressed confidence in its success because families of pediatric cancer patients have been using social media and are very driven—a great recipe for success.

The ECOG-ACRIN Cancer Research Group is also leveraging social media to engage patients and patient-advocates, who are "critical partners," according to ***Ruth Carlos, M.D.***, chair of the ECOG-ACRIN Cancer Care Delivery Research Committee. "Patients are partners," she added, and social media can be used to bring the

patient into the clinical trial realm, not just as subjects but as co-creators and co-developers of trials. Carlos explained that in January 2016, ECOG-ACRIN began a Twitter campaign and posted to invite people to join tweet chats. Participants were mostly professionals and a few patients. After the intervention there were more interactions with and between patients. They became central hubs that others gathered around, Carlos said. "Patients respond to the invitation to be heard," suggested Carlos. Engaged patients serve on patient advisory boards and form a very active community. ECOG-ACRIN hosted a workshop with a broad group of patients and patient advocates and relied on this group to help develop a dissemination strategy for a clinical trial on colorectal cancer. Patients need to "frame the message in a way that will resonate with patients," she said. Social media reaches communities that might not otherwise be engaged, she added.

Diane Dragaud, M.A., ECOG-ACRIN's director of communications, described how ECOG-ACRIN and its members are using social media for the Tomosynthesis Mammographic Imaging Screening (TMIST) Trial, a breast cancer screening trial that will recruit 165,000 healthy women across NCORP and NCTN sites. Participants will be asked to remain in the trial for five years. She noted that the organization is using Twitter and LinkedIn to promote website content, share public information about open trials, link to educational materials for clinicians, announce new trials and published results, and connect with advocacy groups. Twitter is "really a connection forum for our leaders to connect with one another and our members to reach out and connect across the NCTN and NCORP," explained Dragaud. As an example, she presented social media activities to enhance accrual to the E2112 study on metastatic breast cancer, which ECOG-ACRIN is using as a model for other trials going forward. To accrue participants to E2112, ECOG-ACRIN had an ongoing Twitter campaign since 2014, published articles in the oncology press, created a central IRB-approved patient video, and recently launched a recruitment campaign with the Army of Women. "We are very, very close to the 600-patient goal now, and social media has been a great promotional vehicle for raising awareness of E2112 among patient communities, sites, and breast cancer advocacy groups." Despite its success with social media, ECOG-ACRIN must still resolve some issues surrounding its use. ECOG-ACRIN is seeking guidance from the central IRB on its approval requirements for social media content, and exploring new ways to leverage social media to engage in bi-directional conversations with advocacy organizations and patient groups about its ongoing trials

Breakout Session Discussions

After the presentations, attendees rotated through five breakout sessions to discuss the common themes and issues that emerged during the workshop and strategize on ways to address these issues. During these sessions, the general audience in attendance discussed what they perceived to be challenges, root causes, strategies, and resources needed.

Facilitating Social Media Access to Clinical Trials Among Populations Who Experience Disparities

Many presenters spoke of the disparities of underserved populations in clinical trial participation. This breakout session examined how to better engage populations who have limited online engagement (e.g., older populations) to improve their access to clinical trials, and how to build on the high social media use of certain populations (e.g., Hispanics and African Americans) who remain underrepresented in cancer clinical trials.

Challenges	• Low online presence for some underserved groups such as elderly and rural populations

	• High use of social media by minority populations, but still low clinical trial enrollment (e.g., among Hispanics and African Americans)
Root Causes	• Language barriers • Lack of access to social media • Economic barriers • No interest in technology (to use or learn) or physically impaired to use it (i.e., some elderly populations) • Lack of knowledge or awareness • Lack of trust in information and sources
Strategies	• Use inclusive designs and language; appropriately translated • Use text messaging and radio to better reach target populations • Use social organizations and religious groups as proxies to reach otherwise hard-to-reach audiences • Develop flyers that fit the cultural area • Hold classes on social media at local libraries • Push messages to coincide with when people are using social media • Reach out to younger generations or women to reach family members who are not on social media • Stay local and seek feedback to ensure strong messages • Find community leaders to build trust • Reach out to primary care providers and state health department offices • Provide pre-programmed kiosks and tablets at hospitals and centers for patients to use • Find patient stories from different audiences to build trust and gain interest • Tap into graduate schools that do research to identify promising areas • Use existing local events to get the word out • Tap into top bloggers and social influencers of the audiences
Resources and Tools Needed	• Funding • Toolkits to help deliver the message; can be branded at the local level • Grassroots engagement and knowledge of local services • Accessible and affordable clinical trials • Volunteers (e.g., high school students who are prolific users of social media can teach seniors) • Relationships among key stakeholders • Researchers who can help test messages • Resource repository

Harnessing Social Media Tools to Increase Awareness About Tissue and Biospecimen Donation During Clinical Trial Preparation

This breakout session looked at how social media can be harnessed to increase awareness of the need for biospecimen donations for clinical research and what social media resources are needed for these complicated requests.

Challenges	• Lack of awareness and education on the need for tissues (e.g., understanding why researchers need tissue samples) • Requests for biospecimens are complicated
Root Causes	• Lack of messaging • Enrollment fatigue • Mistrust • Perception of lack of caring for patients • Not in patient's control
Strategies	• Harness energy of big support groups • Use videos to increase general awareness • Conduct targeted campaigns • Create messaging focused on the patients who donate (e.g., the heroes)
Resources and Tools Needed	• Social media • Science story • Patient's story

Social Media Strategies to Educate and Improve Adolescent and Young Adult Participation in Research

Adolescent and young adult (AYA) participation in clinical trials is historically low, but social media use by this group is generally high. This breakout discussion examined how to use social media effectively to reach members of this population with respect to their cancer diagnosis and survivorship, and how to inform, educate, and encourage their engagement in research and clinical trials.

Challenges	• AYAs have high social media use but are unsure how to engage around health needs • AYAs have relatively low health care utilization • Low awareness of and engagement in clinical trials
Root Causes	• Social media is not being used by all those who need to connect with AYAs; therefore, it is an untapped resource • Lack of psychosocial support for AYAs to guide them • Lack of funding, in contrast to funding available for older people with cancer • Lack of messaging targeted at their particular age group

	• AYAs don't typically want to engage on this issue
Strategies	• Find out where AYAs are and how they want to communicate on social media about health information • Use multipronged messaging approach (e.g., parents vs. independent); segment by age and stage • Combine social media with other communications tools • Use memes and other media formats that the targeted group uses • Share stories in a visual way • Enhance communication between oncologists and AYAs • Use existing AYA networks • Use hashtags • Use AYA patient navigators in their age range • Communicate with caregivers
Resources and Tools Needed	• Private Facebook groups • Shareable media • Public pages • Research on optimum hashtag use • YouTube • Survivorship data • Tailored AYA resources that are tested for the age group • Tailored messages using the language that this age group uses

Leveraging Social Media to Improve Patient Understanding, Engagement, and Participation in Clinical Trials

A common theme during the conference was the general community's lack of understanding and knowledge about clinical trials. During this breakout session, attendees discussed how social media tools can be used to ethically promote clinical trials as credible therapeutic options, while still communicating to patients the investigational nature of clinical trials, and how social media can be used to educate and engage patients at an early stage.

Challenges	• Lack of awareness and misperceptions about clinical trials • Ethical promotion of clinical trials • Patients are generally not consulted in protocol design
Root Causes	• Fear (e.g., in vaccine research there is fear about contracting the disease if an individual is first healthy) • Doctors don't inform patients of existing trials • Recent diagnosis

	• Lack of health or research literacy • Lack of understanding between trial care vs. standard of care • Lack of access to trial • Confusion about IRB requirements for use of social media, and what patients, patient-advocates, and doctors can and cannot communicate via social media • Confidential protocols • Insufficient gathering of patient input in concept and protocol development
Strategies	• Provide ongoing education • Use patient advisories • Create materials that explain clinical trial process and content • Doctors should discuss clinical trials with all patients as part of standard of care • Use a clinical trial dashboard to point patients to appropriate resources • Gather patient input during protocol development workflow • Use existing NCI resources to direct patients to local health care centers and providers.
Resources and Tools Needed	• Local resources (NCI call centers should forward patients to these resources) • American Society of Clinical Oncology to address challenges by convening focus groups • Patient-advocacy offices • NCTN document showing role of advocates throughout the life cycle of a trial

Mitigating the Spread of Misinformation and Unblinding in Clinical Trials via Patient Conversations on Social Media While Still Ensuring Open Dialogue and Engagement Online

This session looked at strategies for mitigating the spread of misinformation and encouraging the exchange of ideas and information while minimizing the risk of compromising the integrity of trials.

Challenges	• Sharing misinformation • Unblinding
Root Causes	• Lack of filtering by stakeholders • Lack of understanding (e.g., health literacy) • Evolving science and evidence • Competing interests • Fear and mistrust • Bias • Trolling • Information overload

	• Sharing information on symptoms and side effects
Strategies	• Moderate social media channels better and provide training to moderators • Use principal investigators to engage with an authentic voice • Provide transparency • Educate patients about trial design • Revamp consent process
Resources and Tools Needed	• Private social media group for trial participants • Training professional patient navigators • Information monitoring on social media channels • A process to acquire consent to contact potential participants on social media

Conclusion

This two-day conference showed that social media is having a paradigm-shifting impact on clinical trials. While clinicians and other stakeholders have made good use of social media over the past few years, there is a clear need for broadening outreach and ensuring equitable access for all prospective clinical trial patients. Treating physicians and caregivers, as well, will benefit from the use of social media to learn and communicate with their patients and community about clinical trials. The speakers presented many ideas on ways to expand on the use of social media as the different platforms evolve, and they acknowledged that there continue to be challenges. The consensus was that all stakeholders need to be involved, leveraging their knowledge and experience in collaboration, to make this happen. Additionally, presenters stressed over the two days that patients need to be partners, not merely subjects, in trials.

Now is the time to take the collective energy from the conference and move forward.

National Cancer Institute Workshop Planning Team

We would like to extend a big "thank you" to the following people at NCI who generously gave their time to make this workshop a reality:

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At the Crossroads of Social Media and Clinical Trials:

A Workshop on the Future of Clinician, Patient and Community Engagement

June 7-8, 2018

Ruth L. Kirschstein Natcher Auditorium • NIH Campus • Bethesda, MD

Follow on Twitter: ***#ClinicalTrialsSM***

Day 1: June 7

8:00 AM	Registration
8:30 AM	Welcome
	Jeff Abrams, MD, Associate Director, Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute
	Helen Moore, PhD, Branch Chief, Biorepositories and Biospecimen Research Branch; Co-chair, Network for Direct Patient Engagement Cancer Moonshot Implementation Team, National Cancer Institute
8:45 AM	***Keynote Presentation*** **Susannah Fox**, Former Chief Technology Officer, U.S. Department of Health and Human Services *Share, Connect, Engage: Social Media as a Platform for Hope*

SESSION 1: Clinical Trials Go Social – Connecting Trials to the Community

9:30 AM	**Andrea Denicoff, MS, RN - Session Chair** Head, NCTN Clinical Trials Operations, Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute *Clinical Trial Accrual Challenges – Is Social Media Here to Help?*
9:50 AM	**Luke Gelinas, PhD**, Chairperson, Advarra IRB, Senior Advisor, MultiRegional Clinical Trials Center of Brigham and Women's Hospital and Harvard *Ethical Consideration in the Use of Social Media as an Engagement and Recruitment Tool*
10:05 AM	**Mike Fisch, MD**, Medical Director of Medical Oncology, AIM Specialty Health *Rallying Oncologists to Social Media for Clinical Trials: "Not So Fast My Friend"*
10:20 AM	Panel Discussion/Q&A
10:35 AM	BREAK & Icebreaker

11:05 AM	NCI's National Clinical Trials Network (NCTN) Presentations
	Thomas George, MD, Associate Director of Clinical Investigation, University of Florida Health Cancer Center, NRG Oncology
	Jamilah Owens, Communications Manager, Alliance for Clinical Trials in Oncology

SESSION 2: Engaging Patient Communities Online

11:25 AM	**Janet Freeman-Daily, MS, Eng – Session Chair** The ROS1ders *Cancer Communities on Social Media*
11:45 PM	**Gilles Frydman**, One Person Closer, Founder ACOR.org *Using Art to Help Re-humanize the Research Enterprise*
12:00 PM	**Jamie Holloway, PhD**, Clinical Research Advocate, Science 37 *Overcoming Barriers to Clinical Trial Enrollment*
12:15 PM	**Nathaly Gonzalez**, Bilingual Patient Navigator/Community Outreach Coordinator, Georgetown University *Using Social Media to Increase Diversity in Research*
12:30 PM	Panel Discussion/Q&A
12:45 PM	LUNCH

SESSION 3: Clinician Focus – Community Building and Outreach

1:30 PM	**Don Dizon, MD, FACP, FASCO – Session Chair** Lifespan Cancer Institute, Rhode Island Hospital, The Warren Alpert Medical School of Brown University *Clinicians on Social Media: A Call for Engagement*
1:50 PM	**Suzanne Millward, MPH, CHES**, Project Manager, Professional Research Assistant, University of Colorado *Considerations for Effective Virtual Engagement and Using Boot Camp Translation for Improving Clinical Trial Awareness*
2:05 PM	**Jonca Bull, MD**, Vice President, Regulatory Consulting, Global Product Development, PPD *Diversity and Clinical Trials: Social Media – Opportunities and Challenges*

engagement? How can we encourage exchange of ideas and information by the clinical trials community while minimizing the risk of compromising the integrity of clinical trials?