

# Using social media for health research: Methodological and ethical considerations for recruitment and intervention delivery

Danielle Arigo<sup>1,2</sup> , Sherry Pagoto<sup>3</sup>, Lisa Carter-Harris<sup>4,5</sup>, Sarah E Lillie<sup>6</sup> and Camille Nebeker<sup>7</sup>

## Abstract

As the popularity and diversity of social media platforms increases so does their utility for health research. Using social media for recruitment into clinical studies and/or delivering health behavior interventions may increase reach to a broader audience. However, evidence supporting the efficacy of these approaches is limited, and key questions remain with respect to optimal benchmarks, intervention development and methodology, participant engagement, informed consent, privacy, and data management. Little methodological guidance is available to researchers interested in using social media for health research. In this Tutorial, we summarize the content of the 2017 Society for Behavioral Medicine Pre-Conference Course entitled ‘Using Social Media for Research,’ at which the authors presented their experiences with methodological and ethical issues relating to social media-enabled research recruitment and intervention delivery. We identify common pitfalls and provide recommendations for recruitment and intervention via social media. We also discuss the ethical and responsible conduct of research using social media for each of these purposes.

## Keywords

Digital health, social media, health behavior change, Facebook, Twitter, research ethics

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The purpose of this paper is to share recommendations for using social media in recruitment and intervention delivery in health behavior research. These recommendations are based on relevant empirical literature, though little evidence exists to inform the use of social media in this space. In order to fill in existing gaps, we describe and make recommendations based on our extensive experience with using social media for recruitment and intervention delivery in the health domain.

A subset of this information was presented by the authors in a 3-hour pre-conference workshop at the Society of Behavioral Medicine annual meeting (SBM; San Diego, CA, March 2017). The goals of the workshop were to introduce SBM members to basic principles of recruitment and intervention delivery via social media, as well as related ethical considerations, and to help members avoid common pitfalls encountered when conducting this research. These topics were requested by SBM members with interest in social

media research; members identified these as most critical to their current work and noted that there is little available evidence to guide new work in these areas. In response, we were invited by SBM committee organizers to present these topics drawing from our relevant research experience (see Recommended reading).

<sup>1</sup>The University of Scranton, USA

<sup>2</sup>Center for Integrated Healthcare, Syracuse VA Medical Center, USA

<sup>3</sup>University of Connecticut, USA

<sup>4</sup>Indiana University School of Nursing, USA

<sup>5</sup>Indiana University Simon Cancer Center, USA

<sup>6</sup>Minneapolis VA Health Care System, USA

<sup>7</sup>University of California at San Diego, USA

### Corresponding author:

Danielle Arigo, Department of Psychology, The University of Scranton, 800 Linden Street, 205 Alumni Memorial Hall, Scranton, PA 18510, USA.

Email: danielle.arigo@scranton.edu

Twitter: @DaniArigo and @SBMDigitalHlth; @DrSherryPagoto;

@DrCarterHarris; @sbmdecisions; @cnebeker



## Introduction

Social media platforms are increasingly popular for sharing and discussing content among diverse audiences. The most popular platforms (Facebook, Twitter, Pinterest, and Instagram) host millions of users, and recent data show little difference in the proportions of US adults who use these platforms based on education level, income, or developed environment (i.e., urban vs. rural).<sup>1</sup> Platform users are able to view and share information in both traditional formats (e.g., text, photos) and interactive formats (e.g., polls, chats, live video). Users also are able to search for information, target communication to subsets of users, form public and private groups, and link communication between platforms. Most of these features are free to all users, with options to pay for marketing-related services.

Given the high rate at which social media platforms are used for daily information exchange, social media is of increasing relevance to health research. Social media platforms offer the potential to observe as well as reach a large and/or specific audience, for no or low cost, with the possibility of multidirectional communication. Public health organizations have capitalized on this potential through social media-based public health campaigns,<sup>2</sup> and researchers have been able to improve infectious disease tracking and prediction using these platforms.<sup>3,4</sup> Social media platforms also offer unique and cost-effective opportunities for recruitment and intervention in the context of health research, including observational studies and interventions. For example, researchers have used Facebook and Twitter to recruit for and deliver behavioral interventions on a multitude of topics including smoking cessation,<sup>5</sup> weight loss,<sup>6,7</sup> and physical activity promotion,<sup>8</sup> to name a few. Social media-enabled research is particularly well suited for studying health topics that are highly stigmatized (e.g., sexual health) as well as connecting with populations that are hard to reach (e.g., rare diseases).<sup>9–13</sup>

Indeed, numerous systematic reviews show support for the efficacy of social media interventions with respect to health behavior change.<sup>14,15</sup> Consequently, social media platforms may have the potential to increase the reach and cost-effectiveness of recruitment and health behavior interventions, but little guidance is available on how to overcome methodological challenges. In particular, there is little information to inform researchers or regulatory bodies about the ethical concerns unique to recruitment and intervention delivery via social media. Understanding these concerns and how to address them in research protocols is a critical step that should occur early in the research process but may be overlooked due to the newness of research conducted via social media.

Few existing resources offer practical advice for researchers seeking to utilize social media in the

health domain. In this paper, we provide descriptions of methodological challenges in using social media for recruitment and intervention delivery. These recommendations stem from the research literature and our own experiences conducting social media-enabled health research in the United States. We emphasize the importance of conducting and disseminating developmental work, such as feasibility and pilot studies. Finally, we provide suggestions for applying relevant ethical principles to social media-enabled recruitment and intervention delivery. We identify important next steps to advance science in each of these areas. Specific learning objectives for this Tutorial are to:

1. identify common challenges and consider proposed solutions to social media-enabled health research recruitment and intervention delivery;
2. distinguish the advantages and disadvantages of Facebook and Twitter for recruitment and intervention purposes;
3. apply ethical principles when leveraging social media for research; and
4. identify specific next steps to advance the science of social media-enabled health research.

These objectives were selected based on our review of existing literature, our experiences with common uses for and barriers to successful health research using social media, and the most frequent concerns about this research expressed by attendees at our SBM pre-conference workshop.

## Social media-based recruitment

A small number of studies have shown the effectiveness of social media for research recruitment,<sup>16</sup> particularly recruitment into clinically relevant health studies.<sup>17</sup> Social media-enabled recruitment efforts have not always increased the pace of recruitment,<sup>18</sup> however, and some have resulted in unrepresentative or unique samples relative to standard recruitment methods.<sup>19,20</sup> A recent review of medical research studies using social media recruitment showed that only 12 of 30 studies found social media to be the most effective recruitment method (relative to traditional methods), and most of those that showed benefit were observational studies.<sup>21</sup> In contrast, half of the 30 studies in this review found social media recruitment to yield fewer participants than traditional methods; those that showed lower yields tended to be intervention studies.

Several reasons may explain this discrepancy. For example, social media advertisements may require repeated viewing before interested parties take the desired action,<sup>22</sup> and it is not always clear how many views are necessary before members of a given

population take the next steps toward enrollment. If recruitment is slower than expected, various benchmarks may be considered to inform refinements to recruitment materials: overall *impressions* for an ad (i.e., the number of times users see it; see Table 1), the number of people who click on a study link in a given period of time, or the number of people who formally enroll in a study.<sup>23</sup> If the latter is the only benchmark of interest (and feedback from enrolled participants is all that is used to modify recruitment materials), researchers may miss opportunities to refine materials that could capture individuals who viewed or clicked on an ad but did not enroll.

Literature on such methodological decisions in health research is limited. Extant empirical evidence indicates a critical need to understand the social media preferences and concerns of the target population<sup>24</sup> (including the typical timetable for response), and to tailor messaging to the norms of particular platforms,<sup>25</sup> in order to capture the attention and interest of eligible individuals. With no guidance, researchers are left to engage in trial-and-error processes to determine how to generate the best recruitment yield<sup>26</sup> while others may give up after netting low yield. Here we address social media recruitment pitfalls along with recommended solutions related to (1) low recruitment accrual (using Facebook as an example), (2) avoiding non-targeted users, and (3) specific suggestions relevant to leveraging Twitter for research recruitment. We end this section with recommendations for advancing the science of social media recruitment into clinically relevant health research studies.

### Challenge to recruitment: low recruitment accrual

Low recruitment accrual is one of the most commonly cited barriers in clinical research in general,<sup>27–30</sup> and less fruitful than expected recruitment results in reduced power and/or truncated follow-up periods. Suboptimal recruitment accrual on social media may occur for several reasons. For example, the target population may not use social media in large numbers; it may be due to a mismatch between the target population and the social media platform demographic profile of users, or it may be due to the overall presentation (e.g., colors, graphics, language) used in the recruitment ad.

**Proposed solution: Identify and learn the platform(s) most relevant to the target population and learn what information can best assist with recruitment adjustments.** Three popular social media platforms used for research recruitment are Facebook, Twitter, and Instagram, which have different user demographic profiles. Facebook is becoming increasingly useful for reaching middle to older age

**Table 1.** Common terms relevant to using social media for research.

Bystander	A person who, due to their proximity to a research participant, may be included in the research record, but is technically not considered to be a research participant as there is no information obtained about that person that is used to answer the research question specific to a particular study. A bystander does not provide informed consent to have their voice, words, or image included in a research record.
Emoji	Small digital images or icons used to express an idea, emotion, etc., in electronic communication.
Engagement	Social media engagement measures the public shares, likes, and comments for social media efforts on a given platform. Engagement is a common metric for evaluating social media performance.
Facebook	An online social networking service. Users create a personal profile, add other users as friends, exchange messages, post status updates and photos, and receive notifications when others update their profiles. Users can also join groups, which can be open, closed or secret.
Friend	Facebook users connect with other users by becoming a 'friend', which allows each to see the other's posts. Users can send, accept, or decline friend requests.
Follower	Twitter and Instagram users may subscribe to other users' posts — this is known as 'following' and subscribers are known as 'followers'.
GIF	Short for graphical interchange format; short animation that plays on a loop.
Hashtag (#)	Precedes a word or a phrase and is used as a way to bring together information about a topic. Users who search or click on the hashtag will see all public tweets with this hashtag included.
Impressions	The number of times a message is seen. For example, if someone sees a Facebook page update in their news feed and subsequently sees that same update when a friend shares it, this would count as two impressions.
Influencer	An individual who has above-average impact on a specific demographic or topic. Influencer marketing is a form of marketing in which focus is placed on influential people rather than the target market (e.g., asking a top social media influencer in your research area to assist with recruitment by posting to their followers).

(continued)

Table 1. Continued.

Informed consent in research	The purpose of informed consent is to demonstrate the ethical principle of autonomy and respect for a person by providing study information to that person in a manner that is accessible and in a setting that is conducive to good decision-making so they can make a 'informed' choice about whether to volunteer as a research participant. The informed consent process can be conducted in person via an interaction with a member of the research team or via an electronic format whereby the study information is viewed on an electronic device or social media interface.
Instagram	A social media platform that allows users to share pictures and videos either publicly or privately.
Like	Users of various platforms can click a button to indicate that they like (endorse, acknowledge, agree with) a particular post. The number of likes is one indicator of engagement with a given post.
Notification	A message that appears in a user's account to let them know that someone has liked, commented on, or responded to one of their posts. Notifications also may appear for content that a platform algorithm predicts a given user will want to see (e.g., a new video or news story).
Privacy policy	Used to inform consumers about how data will be managed, stored and shared by the entity.
Reach	The number of people who receive impressions; reach might be less than impressions because one person can see multiple impressions. For example, if a person sees a Facebook page update in their news feed and subsequently sees that same update when a friend shares it, this would represent a reach count of one.
Retweet	Passing on someone else's tweet in your posts, so that your followers can see it. Retweeting means that more people will see the tweet.
Social media	Computer-mediated technologies that facilitate the creation and sharing of information, ideas, career interests, and other forms of expression via virtual communities and networks.
Target population	Target population refers to the entire group of individuals to whom researchers are interested in generalizing their conclusions. Advertisements, products, or campaigns intended for an identified group of people are referred to as targeted. Also called target audience.
Tagging	Including someone's user name in a post, which sends this post directly to the user's news feed or notifications.

(continued)

Table 1. Continued.

Terms and Conditions of Service	Agreement that sets forth terms, conditions, requirements, and clauses that a consumer agrees to accept if choosing to use a product such as a social media platform (e.g., copyright protection, data sharing practices, accounts termination in cases of abuses).
Tweet	Message of 280 characters or less sent out on Twitter. Unless tweets are made private, they are seen by anyone who looks at a profile and by a user's followers. Users also see the tweets of people they follow in their news feed. Registered users can post tweets, but those who are unregistered can only read them.
Twitter	A social media platform where users post and interact with messages known as 'tweets' that are restricted to 280 characters.

adults as they make up a considerable subset of Facebook's active user base.<sup>1</sup> As adolescents and young adults make up large proportions of the active user bases for Instagram and Twitter,<sup>1</sup> attempting to reach younger individuals on these platforms may also prove useful. Choosing a social media platform for recruitment requires first understanding the social media habits of the target population. This includes an understanding of variation within the target population with respect to their ability to navigate the chosen platform and to fully comprehend the requirements of a research study, which may influence study outcomes. Table 2 provides a list of advantages and disadvantages of social media recruitment by platform. As many social media users (especially younger adults) use multiple platforms, understanding how often they use each and for what purpose(s) will be important factors that help to determine the ideal platform for recruitment. Further, some platforms (i.e., Facebook and Instagram) allow 'targeting' of ads by user characteristics, which can help ensure the ads are seen by the target audience.

For Facebook in particular, our experience supports the use of several methods to increase recruitment reach and accrual. First, *choosing keywords* that are reflective of the likes and interests found in the target participant users' profiles may increase reach. Keywords can represent any dimension of a person's life such as behavior (e.g., smoking, running) or diet (e.g., vegetarian, diabetic). In a survey study that recruited long-term smokers using the Facebook platform, we used keywords thought to reflect an interest in smoking (e.g., tobacco, cigarettes, e-cigarettes, smoking cessation).<sup>31</sup> In this context, it is important to consider what types of smokers (or other users) might be targeted

**Table 2.** Advantages and disadvantages of social media recruitment by platform.

Platform	Mechanisms to recruit	Advantages	Disadvantages
Twitter	Recruitment Tweet → Retweets <ul style="list-style-type: none"> <li>Tag users and organizations who would find research relevant or interesting who have large follower bases</li> <li>Add a relevant hashtag (i.e., #LCSM<sup>a</sup>)</li> <li>Consider building an online community (i.e., The Clare Project<sup>b</sup>)</li> </ul>	<ul style="list-style-type: none"> <li>Able to loosely target people in a particular field or interest area</li> <li>Ability to ‘pay’ to ‘promote’ the tweet (gets in the feeds of users who don’t follow you)</li> </ul>	<ul style="list-style-type: none"> <li>Sampling bias</li> <li>Not right for all research projects</li> <li>Very little control over the message once posted <ul style="list-style-type: none"> <li>People who do not fit your criteria will see message</li> </ul> </li> </ul>
Facebook	Facebook targeted advertisement	Largest social media platform	<ul style="list-style-type: none"> <li>Sampling bias</li> <li>Not right for all research projects</li> </ul>
Instagram	Ads (owned by Facebook and linked on both platforms)	<ul style="list-style-type: none"> <li>Ability to reach a younger age demographic</li> </ul>	<ul style="list-style-type: none"> <li>Sampling bias</li> <li>Not right for all research projects</li> </ul>

<sup>a</sup>#LCSM = Lung Cancer Social Media.

<sup>b</sup>The Clare Project (Twitter handle: @ClareProject) – project focused on improving the cancer care experience for young adults with advanced cancer.

with keywords. For example, targeting individuals based on their interest in smoking cessation may disproportionately identify a specific subset of smokers who are interested in quitting. Careful attention to these possibilities and their alignment with the desired profile of a study sample should be examined in developmental work before directing resources toward full-scale study recruitment.

In addition, *monitoring a recruitment campaign* via Facebook analytics gives insight into the time of day, days of the week, and associated ad photos that are performing best. This can help the researcher to know when to reset the advertisement parameters (e.g., timing, deleting or replacing poor-performing ad photos) for best performance. In our survey study that used Facebook-targeted advertisement to recruit long-term smokers, we found geographic differences in race.<sup>31</sup> Specifically, as the ad increased reach to rural users, we observed decreased racial/ethnic minority recruitment; conversely, increased urban reach equated to decreased White recruitment. To balance racial representation, we targeted ads by zip codes. By monitoring both the Facebook analytics and accrual rates (including demographics) and adjusting advertisement parameters including turning the ad on and off in certain zip codes, we were able to accrue the target sample size while ensuring equal representation of key demographic characteristics.

### Challenge to recruitment: avoiding responses from non-targeted users

Using social media to recruit for studies that provide incentives can attract responders who are ineligible but attempt to answer the screening questions ‘correctly’ to get into the study and access the incentive.

*Proposed solution: Be selective with information presented in recruitment materials.* One method to counter this is to not reveal the full nature of the study in the recruitment advertisement. For instance, in our previous studies recruiting current or former long-term smokers, the Facebook-targeted ad headline said ‘Would you like to help researchers understand thoughts and opinions about lung health?’<sup>32–35</sup> The age demographics as well as keywords reflective of an interest in smoking (e.g., tobacco, cigarettes, e-cigarettes, smoking cessation) were used to define the target population, but the ad itself was generically focused on lung health. This had the potential to decrease the likelihood that a user responding to the ad would know how to answer the screening questions to meet inclusion and avoid exclusion criteria.

Similarly, if using social media to recruit people to complete a survey for a financial incentive, a single user could attempt to participate multiple times. For example, using Facebook pages and Twitter posts in our efforts to recruit individuals with type 2 diabetes resulted in 20 entries from the same IP address, indicating that they may have been made by the same participant.<sup>36</sup> Ensuring that a survey allows only one response from a given IP address provides the researcher with some protection, though technology-savvy users may find work arounds. Designing a method for careful data screening is essential for ensuring the integrity of survey data; see Konstan et al.<sup>37</sup> for a detailed example.

### Challenge to recruitment: reaching the target audience on Twitter

Twitter is a popular platform that offers distinctive advantages, though utilizing it effectively for recruitment requires a targeted strategy. Unlike Facebook



and Instagram, Twitter feeds are public unless specifically set to be viewable only to followers. This allows users to reach large audiences beyond their own followers. Even if your follower list is large, however, if it was not built with the specific target audience in mind, it may not produce sufficient recruitment dividends. Carefully crafting tweets (in 280 characters or less), following some of the suggestions below, can result in tremendous reach and increases the odds of recruitment.

**Proposed solution: Include the username of high-profile users who are influencers for your target population.** In one instance of targeting influencers (see Table 1), O'Connor and colleagues<sup>38</sup> engaged new mothers age 35 or older on Twitter by tweeting at the accounts of parent- and child-focused organizations and celebrity mothers with large lists of followers (i.e., including their usernames, or handles, in recruitment tweets). This method of recruitment led 529 Twitter users to access the study survey and 299 to complete the entire survey over 11 weeks. Before tweeting at influential users, researchers might consider sending a message as a courtesy to briefly explain the research and asking for their assistance through a retweet. This could increase the possibility of their engagement and potential for retweeting. Examples of recruitment tweets likely to result in low versus high accrual into a survey study are shown in Figure 1.

**Proposed solution: Use relevant hashtags.** Hashtags (#; see Table 1) can increase a tweet's reach by serving as a gateway to all those following the hashtag. The key is to find a hashtag that has a large, relevant following. The right hashtag not only increases the number of people who see the tweet but could increase the potential for those users to retweet your recruitment tweet. Commonly used hashtags for specific topics can be

found at sites like [hashtags.org](https://hashtags.org), [twubs.com](https://twubs.com), and [twazup.com](https://twazup.com), and healthcare-related hashtags can be found in the Healthcare Hashtag Project at [symplur.com](https://symplur.com). While it can be a challenge to craft a tweet in 280 characters or less and include relevant hashtags and a link to your survey or website, some forms of shorthand and abbreviations are common on Twitter. Becoming familiar with the norms on Twitter can help in crafting engaging recruitment tweets, as can working to make posts understandable and memorable, which will ensure that they are 'sticky' (i.e., they catch on).<sup>39</sup>

In addition, it is important to consider points such as the frequency of recruitment tweets and how followers of a particular hashtag use and interact with it. In our experience, it has been beneficial to space out recruitment tweets so that the recruiting account does not appear to post only this type of content (as many users will decline to follow or retweet in this case). Some hashtags also tend to be used by intact communities, which can resemble live communities in their development of norms.<sup>40</sup> If a hashtag is used by a small, active, and/or tightly knit community, researchers' use of the hashtag merely for recruitment purposes may be perceived poorly. Again, we believe it is important for researchers to understand both the habits of the target population and the customs of a particular platform in order to maximize recruitment accrual.

### Next Steps: advancing the science of social media recruitment

The success of social media recruitment may be linked to type of posts and specific platforms, thus research comparing social media recruitment strategies is needed to identify the best approaches. For example, studies could compare paid ads on different platforms or compare the use of intact communities (e.g., large

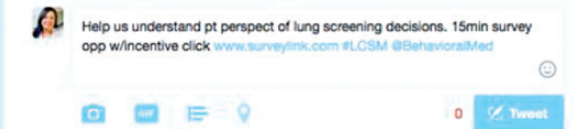

Example of Well Crafted Tweet	Example of Suboptimal Tweet
 <ul style="list-style-type: none"> <li>▪ Clear and concise purpose of the study (i.e. "understand patient perspective of lung screening decisions")</li> <li>▪ Draws the reader in by asking for help (i.e. "help us understand")</li> <li>▪ Shares expected time to complete the survey</li> <li>▪ Shares an incentive is attached to completion</li> </ul>	 <ul style="list-style-type: none"> <li>▪ Asks reader to do something (i.e., take our survey") with vague, nondescript language which increases the likelihood reader may be hesitant to click the unknown link</li> <li>▪ Tweet is short and leaves potential characters on the table by not using 71 remaining characters to be descriptive and engaging</li> </ul>

Figure 1. Example of well-crafted versus suboptimal tweet.

topic-driven Facebook groups) with paid ads. Use of influencers is another unique approach that has received very little study. Little is known about the characteristics of influencers most likely to produce high recruitment yields and whether and how much incentive is necessary. Further, additional research is needed regarding the use of incentives in social media recruitment to determine what works best. If using social media as a recruitment method in addition to more traditional recruitment methods, researchers also should compare approaches on yield, demographics, and other patient characteristics. The optimal approach likely varies by the target population being recruited.

An optimal method for ensuring representativeness may involve combining traditional and social media methods of recruitment.<sup>41</sup> In addition, specialty social media platforms (e.g., Grindr) should also be explored.<sup>42</sup> And if recruitment occurs in stages, participants could be incentivized to share study information with their social networks. This may increase recruitment accrual (if shared information encourages enrollment) but could affect the integrity of the research by changing the expectations of participants in later recruitment stages. Finally, cost-effectiveness of different social media recruitment approaches should be evaluated relative to each other and traditional approaches.

### *Social media-delivered interventions*

Delivering behavioral interventions via social media may be more feasible and cost-effective than traditionally delivered approaches. For example, offering an intervention through social media eliminates the need for clinic visits (which are riddled with barriers like transportation, childcare, and scheduling conflicts) and allows content to be embedded into people's regular social media habits.<sup>43</sup> Given the popularity of social media and the time users spend on platforms each day, a significant opportunity exists to use these platforms to improve intervention receipt, engagement, and retention. How best to take advantage of social media for behavioral interventions is still unclear, and many methodological challenges exist. Three major challenges include: (1) platform selection; (2) lack of control over settings and features; and (3) participant engagement. These challenges are discussed along with recommendations for overcoming them. Developmental work that specifically addresses these issues is described and may be essential to advancing the science more quickly.

*Challenge to intervention: platform selection.* As noted, each social media platform varies in features, user characteristics, and reasons for use. Most importantly,

the social media platform used for intervention delivery has to be acceptable to the target population. Depending on the study topic, people might find it most acceptable to participate on the platform they use frequently and are familiar with; alternatively, some might prefer one they do not currently use, perhaps for privacy reasons. For example, people with a highly stigmatized condition (e.g., HIV/AIDS) might prefer to use an anonymous account on a platform their friends and family members do not use, to completely separate their participation from their usual social media activity. While private groups on most platforms hide membership and engagement from a user's 'friends,' even the threat of accidentally posting something on the wrong page could deter participants from engaging freely. We have observed that some platforms make moving between multiple accounts easy (e.g., Twitter) while others forbid multiple accounts (e.g., Facebook), which may be a factor in matching the platform to the intervention and participant preferences.

Another factor in determining the appropriate platform is style and format of posts. Facebook and Twitter typically involve text-based posts that may or may not include images, videos, and 'GIFs' (i.e., graphical interchange format). On the other hand, every post on Instagram has an image or a video and may or may not include text. The best match may depend on how conducive the intervention content is to being conveyed via image and/or video, as well as participant preferences for content consumption. Video duration and post character limits also vary across platforms, with norms ever changing. Intervention content should be designed to stay current with norms or risk being ignored or disapproved of by participants, especially if they are seasoned users of the platform.

*Proposed solution: Let the target population inform platform choice.* The decision about platform should be guided by the target population in developmental work where each platform is explained and features and privacy settings are reviewed. Researchers should have a strong working understanding of each platform and a vision for how the intervention might be delivered on that platform, ideally including a sample feed. The pros and cons of each platform can then be discussed and suggestions solicited for how to optimize the intervention on the preferred platform.

*Challenge to intervention: lack of control over settings and features.* Commercial platforms typically have the benefit of many years of usability refinements carried out by large teams of programmers with extensive expertise in user experience and design. From a usability standpoint, this makes commercial platforms superior to

researcher-developed platforms, but the downside is that researchers have no control over settings and features. Commercial platforms can and do change settings, features, and functionality on a regular basis without notice, which can affect intervention implementation, receipt, and engagement data collection. For example, Facebook recently added a function where users can access the full range of emoji reactions to post comments, whereas previously only the 'like' reaction was available for comments. This has implications for engagement data collection; now more data on engagement with posts are available but may not be collected depending on whether the tool used to collect data has been updated accordingly.

Most platforms that enable the creation of groups also have proprietary algorithms that dictate how often posts from a group will appear in an individual member's feed. Generally, members who engage more with content in a group will see more group content in their feed and those who engage less will see less content over time. This means intervention receipt will not be balanced across participants and gives researchers very little control over the problem.

*Proposed solution: Promote engagement with specific platform features.* One way to ensure a member sees a post is to tag them in the post which triggers a notification to their account. However, tagging is typically only used sparingly on certain platforms, and so would not be appropriate to do for all or most posts as a way to increase views. In our experience, the best way to ensure that participants see posts is to verify that they engage regularly with posts (e.g., through liking or commenting on a post). This can be challenging and requires a fair degree of developmental work on the intervention content. Some platform algorithms also suppress posts made by a user who posts frequently. This impacts intervention receipt to the extent that the interventionist posts frequently. The degree of suppression may depend on the degree of engagement on posts, with more suppression when subsequent engagement has been low. A highly engaging feed can provide some protection from view suppression, but this will require iterative pretesting of the feed to ensure it solicits high engagement. Platforms not only conceal their algorithm but change it without notice, making it particularly challenging to work around.

We have observed that regular tracking of post views and engagement can help to flag problems during the intervention. Having participants set up notifications before the intervention can ensure they receive a notification when a new post appears in the group, which could enhance intervention receipt and engagement. Developmental work should address participant preferences regarding notifications and preferred modality

(e.g., in app, phone pop-up) to ensure that notifications are acceptable and do not inadvertently provoke disengagement or drop-out.

*Challenge to intervention: engagement.* Perhaps the most significant challenge in social media-delivered behavioral interventions is participant engagement. Several studies have shown that greater engagement is associated with improved outcomes, but engagement is highly variable, with some people engaging daily and others engaging very little.<sup>7,44–48</sup> We also know little about the type of engagement that is most meaningful. A recent study of a weight loss intervention deployed via Facebook found that the more frequently a participant posted (e.g., about their progress, questions for the counselor or group), the more weight they lost.<sup>49</sup> Other types of engagement were not associated with weight loss, including posting about setbacks without a plan to get back on track, recipes, and peer support. Because certain types of participant posts are related to better outcomes, guiding participants on what to post could be useful. It might also help participants who are new to online groups and unsure of the posting expectations.

Research on predictors of engagement in online interventions is still nascent,<sup>43</sup> though several studies have examined characteristics of intervention posts that are associated with higher engagement. One study that examined posts in a Facebook weight loss group found that those soliciting weight reports, those prompting participants to give advice to others, and those with polls received more engagement than posts of recipes or nutrition information.<sup>50</sup> Another study examined engagement in smoking cessation online communities and found that engagement with different post types depended on a participant's readiness to change; those who were contemplating change engaged more with decisional balance posts (i.e., considering the pros and cons of change), whereas those preparing to take action engaged more with posts intended to raise consciousness about the process.<sup>51</sup> This makes an argument for ensuring that posts are theory-driven and reflect the varying levels of motivation present in the group.

Engagement by post type has also been examined in online groups that are not led by counselors or coaches. For example, a study of peer-led diabetes support groups on Facebook examined engagement with participant-initiated posts and revealed that those expressing negative affect, affirming positive identity in spite of disease, and those asking the group a question solicited the most discussion.<sup>52</sup> This work could inform how to guide participants on ways to engage that are likely to solicit feedback. In addition to post content, the media used in a post appears to impact



engagement. A study of posts on the National Cancer Institute Facebook page showed that posts received more engagement if they included images as opposed to videos, text only, or links.<sup>53</sup> These studies provide some insights on ways to design posts to maximize engagement, but more research is needed to obtain a comprehensive understanding of engagement in online communities.<sup>54</sup>

Other factors likely to influence engagement include the type of intervention (e.g., educational, supportive, counseling), social media experience of the target population, group size, and presence of close ties in the group. Our work has revealed that social media users are used to seeing content in specific formats on their preferred platform and have likely developed preferences for what they choose to read or scroll past. Participants' comfort levels engaging may also vary greatly depending on the topic. For these reasons, developmental work with the target population is recommended prior to testing the efficacy of a social media-enabled intervention. Whether developing novel intervention content or translating pre-existing content into a format that is suitable for social media delivery, a user-informed process will identify potential engagement barriers and lend insights into how to solve them.

*Proposed solution: Carefully design developmental research.* Developmental work to identify and overcome challenges to the intervention may include focus groups, key informant interviews, and/or small single-arm pilot studies. Focus groups and key informant interviews can be used to obtain feedback on moderator characteristics (e.g., gender, peer vs. professional), use and frequency of notifications, frequency of posting, group size and composition, and length of the program. They can also be used to evaluate acceptability of intervention posts (e.g., content, format) and activities (e.g., chats, challenges, goal-setting). This can be accomplished by having participants review, rate, and respond to sample posts in the focus group. In reviewing posts, participants can also react to how likely they would be to comment on or share a post and the reasons they would or would not. In addition, participants can make suggestions for discussion topics they would be likely to engage in, resources they would like in an intervention feed, and ways to encourage group members to engage. For more extensive feedback on the feed in its intended form, participants can be asked to follow the feed for a week and provide feedback via comments on each post before attending the focus group.

Once intervention posts are refined based on focus group and/or informant interview data, a single-group pilot test of a truncated version of the intervention can

provide additional acceptability data and an initial evaluation of intervention engagement.<sup>7</sup> Focus groups conducted after the pilot can be used to solicit feedback on posts that received little or no engagement, to solicit barriers and facilitators to engagement, and to gather suggestions for modifications. The data collected from the developmental phase along with emerging literature on engagement in online social network groups can be used to make intervention refinements prior to initiating the fully powered trial. A science of engagement is certainly needed and thus publishing these developmental data is essential to inform the efforts of investigators doing similar work.<sup>54</sup>

### *Next steps: advancing the science of intervention delivery and engagement*

As noted, engagement with social media intervention content varies, and low engagement is a key barrier to successful intervention in this context.<sup>14</sup> Influences on engagement have not been well studied. A fundamental question is the directionality of the engagement–outcome relationship. For example, participants who demonstrate greater overall engagement in social media-enabled weight loss interventions (e.g., more posts to a feed) lose more weight than participants who show less engagement.<sup>55</sup> Engagement may be either a by-product or a driver of treatment success. Future research should *examine temporal relations* between engagement and the behavioral changes expected to underlie outcome improvement (e.g., ‘lapses’ in diet adherence in the context of obesity treatment).<sup>56</sup> An examination of mediators of the engagement–behavior change relationship and moderators (such as when, for whom, and with what specific content) can improve our understanding of the relationship between engagement and outcome in a way that could inform improvements to interventions.

Our developmental work in this area has shed some light on the engagement–outcome relationship.<sup>57,58</sup> We conducted time-sensitive analyses to control for a participant's overall engagement (i.e., comments, posts) in a physical activity intervention and tested for effects of week-to-week change from that participant's average. During weeks when a participant's engagement was higher than his or her average, his or her physical activity also was higher than his or her average.<sup>57</sup> Further, a participant was less likely to skip workouts *following* weeks when they were engaging more than their average.<sup>58</sup> This work provides preliminary temporal evidence that engagement with an intervention may precede (and thereby, drive) behavior change, and larger, longer-term investigations are needed.

A second recommendation for future research is to *differentiate the processes by which social media*

*interventions promote health behavior change*, above and beyond the content of the intervention itself. Social media platforms can facilitate both explicit communication and implicit impressions of norms and expectations between users,<sup>59,60</sup> which can affect health behavior in distinct ways. Explicit communication can occur via information-sharing posts and direct contact (messages, comments) between users; norms and expectations can be communicated in these forms, but also are conveyed through photos, videos, and indicators such as likes, retweets/shares, and other reactions.

Any combination of these can activate processes such as social support, accountability, friendly competition, or social comparison. These processes are not equally motivating or helpful across participants or specific situational contexts.<sup>61–63</sup> If one or more of these processes is activated for the wrong participant and/or at the wrong time, the intervention could have little (or even negative) effect on motivation or behavior. In the context of promoting physical activity, comparing one's progress to that of other intervention participants can be either motivating or discouraging and could lead to disengagement from treatment if it is not effectively addressed.<sup>64</sup> We have seen little empirical attention devoted to understanding these distinct processes as mechanisms of action in social media interventions, including their independent, interactive, or synergistic effects or individual differences in participant response. It is also unclear if these processes are the same or different from the group process that occurs in traditional face-to-face interventions. Greater attention to the processes that underlie social media communication and intervention effects will advance the science of interventions in this space.

### **Broader challenges to social media recruitment and intervention: designing ethical social media research**

When designing research leveraging social media platforms, attention must be paid to the foundational ethical principles of autonomy, beneficence, and justice. These principles are demonstrated when determining how to: (1) obtain informed consent within a social/digital domain; (2) assess and mitigate the probability and magnitude of potential harms; and (3) ensure those who stand to benefit from the research are included as participants. In addition, social media researchers should be aware of and consider the rights of 'bystanders' who may be inadvertently involved due to their relationship to a study participant (e.g., a follower or friend of a participant; see Table 1).<sup>65,66</sup> Likewise, as the platforms themselves are not under the researcher's control, data management can be challenging. Given the variety of possible research designs that could

involve social media and limited ethical and regulatory guidance, we recommend that researchers consider the following, specific to roles and responsibilities.

#### *Proposed solution: Consider differential risks to platform users*

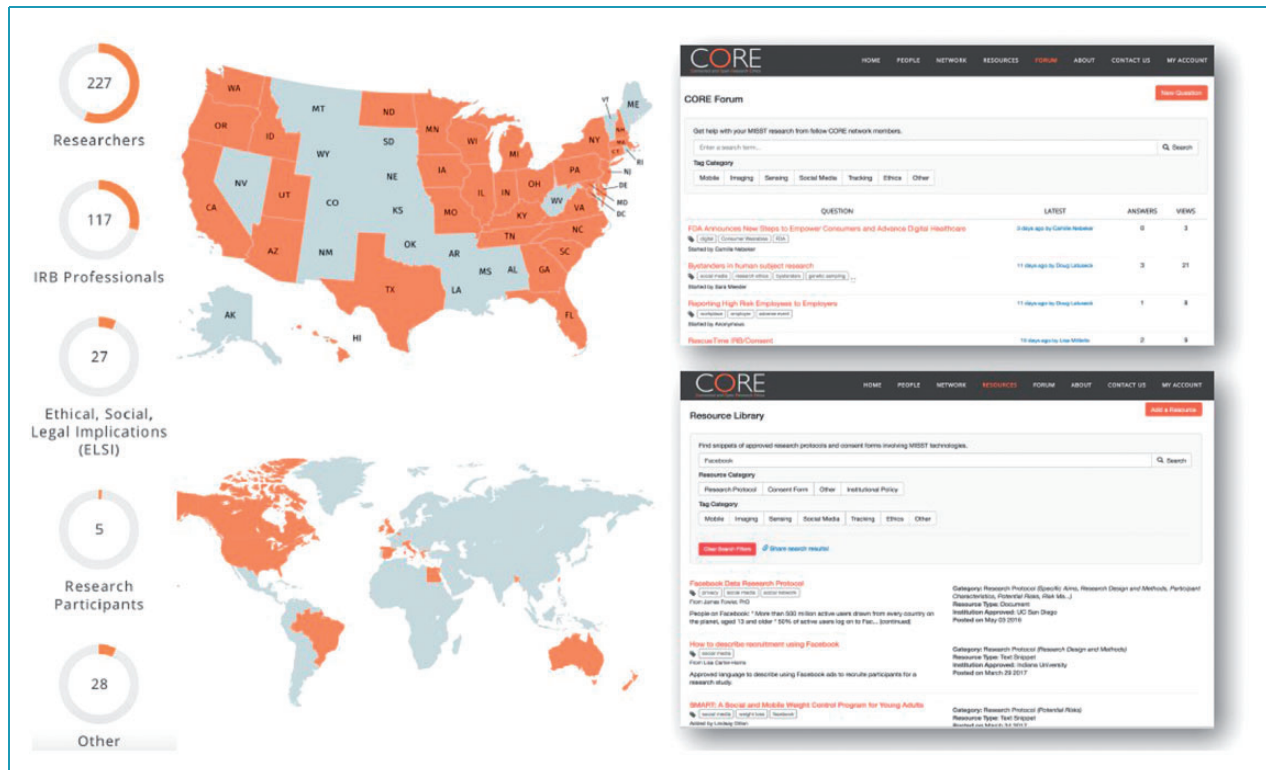
Researchers should evaluate the nature of participant involvement and prospectively consider the potential risks to individuals and, if relevant, to bystanders and social media communities. For example, when a person is not a research participant, to what extent are privacy protections and considerations for data confidentiality important – both for the individual and for those who may be peripherally involved due to their interactions with a participant (e.g., bystanders)?

#### *Proposed solution: Tailor communication about risks and expectations*

Researchers are ultimately responsible for shaping the ethics of this cutting-edge research. To do this, gathering evidence to identify the probability and magnitude of potential harms to participants and bystanders is necessary. In addition, identifying best practices for conveying study information to prospective participants in a way that is accessible and meaningful will facilitate improvements in the digitally delivered informed consent process. As social media affords great potential for recruiting young adults, it is important to consider their understanding of informed consent and their expectations for privacy, which might be distinct from that of older adults.<sup>42</sup>

#### *Proposed solution: Work closely with regulatory bodies to develop standards and update them as needed*

As social media use in research is relatively new, regulatory bodies may not be sufficiently familiar with the tools and methods to properly evaluate the study. Relative to regulators, researchers are often better able to evaluate the study risks and risk management strategies due to their familiarity with the technology. This knowledge puts the researchers in a unique position of being able to educate the entities charged with reviewing these studies (such as Institutional Review Boards). We recommend that researchers be diligent with staying abreast of changes so that they can communicate this information to their regulatory boards and research participants. This may mean adding people to the research team who are: (1) experienced with the technologies being used; (2) familiar with a platform's corporate terms and conditions as well as privacy policies (including those specific to data



**Figure 2.** The CORE interface.

sharing); and (3) able to assist with navigating the complex ethical and regulatory landscape that is developing within this emerging research ecosystem.

### *Resources to support social media-enabled and other digital health research*

Practical and accessible guidance for researchers designing (and regulatory boards reviewing) social media-enabled studies are sparse but are on the rise. In 2016, Harvard University's Catalyst group provided some recommendations,<sup>67</sup> and other resources can be found from the British Psychological Society<sup>68</sup> and the UK National Institute for Health Research.<sup>69</sup> In 2015, the Connected and Open Research Ethics (CORE) initiative was launched with support from the US-based Robert Wood Johnson Foundation. The web-based CORE platform includes a global virtual community of researchers, technologists, and regulatory entities who are sharing resources to foster the ethical design and responsible review of research with emerging technologies, including social media (see Figure 2 for an example of the CORE interface).<sup>70</sup>

### **Summary**

Social media platforms offer health researchers a wealth of opportunities for increasing the efficiency of

recruitment efforts and delivering low-cost, scalable behavior change interventions. To date, however, the research literature has offered little guidance on best practices in these domains or the unique ethical issues that arise. This paper begins to fill this gap by summarizing some of the relevant existing research and providing recommendations for health researchers interested in using social media tools for study recruitment and intervention deployment. As an educational paper written by researchers in the United States, the focus is more narrowly on US-based social media trends. However, we anticipate that these recommendations are generalizable to countries outside of the United States. We encourage researchers globally to help increase awareness of emerging resources in this area to maximize what we can learn from others' experiences and advance the potential of social media-enabled health research.

Based on existing literature and our research experiences, our overarching recommendation is to *carefully consider the appropriateness, advantages, and limitations of available platforms specific to a target population and purpose*. Lack of attention to these aspects of social media increases risk for methodological problems and ethical challenges, including possible privacy violations. Privacy risk is a key concern among research participants,<sup>71,72</sup> though nearly half of all social media users report difficulty understanding or managing their

individual privacy settings.<sup>73</sup> In addition, our experience indicates that privacy policy features and restrictions change frequently, and often change without public announcement or in-platform notifications. We encourage researchers who intend to use social media for recruitment or intervention to *monitor changes to the terms and conditions of service and privacy policies* (e.g., by following each platform's social media pages, staying abreast of technology news sites) and/or include individuals on the research team with appropriate expertise to do so. Likewise, regulatory board members and grant reviewers should evaluate the investigative team's experience with using social media as a research tool and expect experts on the team, as this is an area where team science is essential.

In general, careful developmental work designed to understand the target population's social media habits, preferences, and needs with respect to ethical considerations will maximize the return on investment. Such work will provide necessary insight into methods for optimally tailoring a recruitment or intervention plan to the target population's needs and preferences. We strongly encourage researchers who conduct this type of developmental work to *publish their findings*. For example, we have conducted preliminary research to investigate: (1) smokers' responses to various types of recruitment ads,<sup>74</sup> (2) engagement with distinct types of weight loss intervention content on Twitter,<sup>7</sup> and (3) the ethical, legal, and social concerns associated with technology-enabled research among regulatory stakeholders and groups underrepresented in biomedical and behavioral health research.<sup>75,76</sup> In particular, there is need for a more sophisticated understanding of social media use among populations with elevated health risk who often are underrepresented in health research (e.g., racial/ethnic minority or rural users) and how best to use social media to meet their unique needs. A larger, more diverse literature will prevent researchers from wasting resources by replicating failed approaches or 'reinventing the wheel' and help to push the field of social media-enabled health research forward more quickly.

### Recommended resource: *Connected and Open Research Ethics Platform*

Consulting the CORE website (<https://thecore-platform.ucsd.edu>) during project development may be particularly helpful. CORE provides a network of experts (500+ researchers, ethicists, regulators, technologists from the United States and abroad), access to a question/answer forum, and resources related to consent and protocol language including descriptions for social media-enabled research (see Figure 2).

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**ORCID iD:** Danielle Arigo  <http://orcid.org/0000-0002-7807-5913>

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