Using Social Media as a Research Recruitment Tool: Ethical Issues and Recommendations

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Abstract

The use of social media as a recruitment tool for research with humans is increasing, and likely to continue to grow. Despite this, to date there has been no specific regulatory guidance and little in the bioethics literature to guide investigators and IRBs faced with navigating the ethical issues it raises. We begin to fill this gap by first defending a non-exceptionalist methodology for assessing social media recruitment; second, examining respect for privacy and investigator transparency as key norms governing social media recruitment; and, finally, analyzing three relatively novel aspects of social media recruitment: (i) the ethical significance of compliance with website 'terms of use'; (ii) the ethics of recruiting from the online networks of research participants; and (iii) the ethical implications of online communication from and between participants. Two checklists aimed at guiding investigators and IRBs through the ethical issues are included as Appendices.

Keywords

Research; ethics; social media; recruitment; privacy; transparency

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1. Introduction

Social media sites – Facebook, Twitter, Grindr, Instagram, LinkedIn, and other similar online spaces – offer various platforms for connecting and sharing interests and information, while allowing users to maintain physical separation and a degree of anonymity. For the purpose of this article, we will define 'social media' as internet-based applications that permit users to construct a public or semi-public profile and create and maintain a list of other users ('friends') with whom they may share content and participate in social interactions and networking (Boyd and Ellison 2008; Kaplan & Haenlein 2010). With increased general use and penetration of social media platforms, investigators are exploring ways to utilize social media in research; in particular, social media is emerging as a promising way to identify and recruit potential participants for clinical trials and other forms of human subjects research (Gearhart 2015). Social media is attractive in this context because it may enable investigators both to reach wider segments of the population than may otherwise be accessible and to target individuals on the basis of personal information that, in many cases, allows researchers to infer their eligibility for particular studies.

Despite its growing popularity as a recruitment tool, there is no specific regulatory guidance and few resources to guide IRBs, investigators, and others on the use of social media for research recruitment. (Andrews 2012; Adair 2015).[2] Moreover, while some IRBs have policies on social media recruitment, most do not, and even among existent policies there is no clear consensus over how to identify and approach the most pressing issues.[3] This is problematic, since navigating social media recruitment requires applying legal and ethical norms sensitively in a context that may be unfamiliar to investigators and IRBs. In this article we examine the conceptual and ethical issues involved with the use of social media in recruitment to research and present a set of practical recommendations for investigators and IRBs. Our focus here is purposefully narrow. We limit our analysis primarily to ethical issues that arise when using social media as a method for identifying and contacting potential research participants, or as a platform for communication between currently enrolled participants, leaving aside ethical issues surrounding online research using social media more generally (e.g., data collection over social media sites) as well as issues that arise when obtaining participant consent online (e.g., online tools and methods for ensuring comprehension and confirming participant identity). We have developed the recommendations we offer into a practical guidance document for investigators and IRBs, including two checklists for facilitating proposal and review of social media recruitment, both of which are presented here as Appendices.[4]

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[2]While the Secretary's Advisory Committee on Human Research Protections, a federal advisory committee of the Department of Health and Human Services, has issued non-binding recommendations on internet research generally (SACHRP 2013), those recommendations do not cover recruitment to research or clinical trials specifically in sufficient detail to yield actionable advice on many important issues that concern us here.

[3]Online searches revealed the existence of IRB policies or guidance documents addressing social media recruitment from the University of Pennsylvania, Cornell University, Indiana University, Johns Hopkins School of Medicine, Purdue University, Quorum Review, and The Feinstein Institute for Medical Research (see Works Cited for references and links). There is wide variation among these documents over the topics covered as well as the degree of analysis provided.

[4]The guidance document is "The Use of Social Media in Recruitment to Research: A Guide for Investigators and IRBs." https://catalyst.harvard.edu/pdf/regulatory/Social_Media_Guidance.pdf.

We begin with a brief overview of the empirical literature on the effectiveness of social media as a recruitment tool. In Section 2, we advance a methodology for evaluating social media recruitment proposals, grounded in the belief that social media recruitment ought to be assessed in terms of the same general ethical principles as traditional recruitment, namely, beneficence, respect for persons, and justice. However, we also analyze what we take to be the two most salient normative considerations for evaluating social media recruitment, which are more specific components of the general principles: (1) respect for the privacy of social media users, and (2) investigator transparency. In Section 3, we consider several detailed cases to illustrate our methodology, as well as the substantive application of the ethical principles we advocate. In Section 4, we examine three issues that we think are relatively unique to social media recruitment and so likely to be less familiar to investigators and IRBs: (i) the ethical significance of compliance with website business rules or 'terms of use'; (ii) the ethics of recruiting from the online networks of current or potential research participants; and (iii) the ethical implications of certain forms of post-enrollment online communication from and between participants. The article thus has two overarching aims: to examine the issues conceptually, asking whether and in what ways social media requires a shift in conceptualizing the ethical aspects of recruiting human subjects for research; and to yield concrete, practical ethical guidance and directives for investigators and IRBs involved in proposing and evaluating social media recruitment.

1.1. Why social media for recruitment?

Recruitment to research remains a perennial challenge. By some counts, up to 60% of all clinical trials are delayed or cancelled due to lack of enrollment, slowing the progress of socially valuable research and at times resulting in research participants being exposed to risks, burdens, and inconvenience for no benefit (Puffer & Torgersen 2003; Wertheimer 2013). Further, researchers face particular problems with specific hard-to-reach populations, such as patients with rare medical conditions, or women at particular stages of pregnancy (Ramo and Prochaska 2012), among others. Additionally, traditional methods, such as use of print, radio, and television advertising, can be costly and often do not remedy low participation rates (Fenner et al. 2012).

While empirical research on the effectiveness of social media recruitment is still in its infancy, several studies offer early signs of promise (Shere et al. 2014; Frandsen et al. 2014; Akard et al. 2015; Goadsby 2013; Fenner et al., 2014; Tweet et al. 2011). To date social media recruitment techniques have shown effectiveness for HIV vaccine clinical trials (Sitar et al. 2009), occipital nerve studies (Goadsby 2013), pediatric cancer research (Akard et al. 2015), depression prevention studies (Morgan et al. 2013), and smoking cessation research (Frandsen et al. 2014; Heffner et al. 2013), among others. Perhaps more striking, they have also shown effectiveness with historically hard-to-reach populations, such as young cancer survivors (Gorman et al. 2014), gay Latino males (Martinez 2014), the deaf community (Kobayashi et al. 2013), and sufferers of low-incidence diseases, such as spontaneous coronary artery dissection (Tweet et al. 2011; Ramo and Prochaska 2012). While unlikely to be the sole remedy for the challenges of recruitment, social media is, and will increasingly become, an important tool in the recruitment arsenal, and therefore calls for ethical and

regulatory guidance that can facilitate the appropriate implementation of social media recruitment techniques.

2. Methodology and substantive ethical considerations

In this section we propose a methodology for evaluating social media recruitment proposals, and identify and discuss the substantive normative considerations that we take to be most salient in this context. As with all human subjects research, federal and state laws govern social media recruitment activities; these legal requirements do not differ when applied to social media. Because there are no specific regulations applicable to social media recruitment, we focus here on the ethics.

Before proceeding further we distinguish two basic types of recruitment activity: passive and active. *Passive recruitment* involves distributing recruitment materials (ads, posters, flyers) with the aim of attracting potential participants to contact the research team for more information and for consideration of enrollment. By contrast, *active recruitment* occurs when research staff approach and interact with specific individuals with the aim of enrolling them in research, usually on the basis of knowledge of characteristics that would make them suitable candidates for particular trials.

Both passive and active recruitment have social media and more traditional 'off-line' correlates. Posting flyers in subways or buses is a popular form of traditional *passive off-line* recruitment, while placing advertisements in health or patient support group websites is a form of *passive online* recruitment. Approaching an oncology patient in clinic for trial enrollment on the basis of the research staff's knowledge of his or her disease state is an example of traditional *active off-line* recruitment, while emailing a member of a patient support website for breast cancer on the basis of her online activity and membership in the group is an example of *active online* recruitment.

2.1. Non-exceptionalism as the default

A key component of our approach is that, whether active or passive, social media recruitment should be evaluated in substantially the same way as more traditional analogue or 'off-line' recruitment. When planning (as an investigator) or reviewing (as an IRB) a social media recruitment technique, we propose the following strategy. First, whenever possible, identify a more familiar off-line variant or equivalent of the social media technique being proposed. Second, identify the substantive ethical considerations that bear on the off-line version and bring them to bear on the online version (see below, Section 2.2). Finally, identify any ways the online version differs from the more traditional off-line equivalent, and evaluate this difference in terms of relevant ethical norms and considerations. In short, we suggest striving to normalize social media recruitment techniques while remaining sensitive to their potentially novel aspects by, first, making their resemblance to more traditional off-line recruitment explicit; second, applying the appropriate ethical considerations and scrutiny; third, determining whether social media recruitment differs from off-line recruitment in ways that warrant further review.

There are two justifications for this non-exceptionalist approach. The first is conceptual. Like off-line recruitment, social media recruitment is governed by the foundational norms of research ethics: beneficence, respect for persons, and justice. The second reason is practical. Normalizing social media in the way we suggest, by comparing it to off-line recruitment, can help investigators and IRBs get their bearings in a context that may be less familiar and may help them isolate any aspects of social media recruitment that are potentially novel and require greater scrutiny. Ideally, this can serve to make investigators and IRBs who might otherwise be wary of social media recruitment more comfortable approaching it, which in turn can help facilitate use of this important recruitment tool. We illustrate our methodology below.

2.2. Substantive ethical considerations

While social media recruitment is governed by the same foundational norms that govern more traditional analogue recruitment, the 'embedded' and interconnected nature of social media does provide a new, potentially unfamiliar context for the application of these principles, one that demands sensitive application of these norms and the recognition that their operational implications may, in these contexts, differ. Our view is that the most salient ethical considerations fall into two categories: (i) respect for the privacy and other interests of social media users and (ii) investigator transparency. Because in our view ethical analysis of essentially all cases of social media recruitment involve application of *both* privacy *and* transparency considerations, we unpack both of these concepts before illustrating them in greater detail in Section 3.

2.2.1. Respect for privacy and other interests—Respect for privacy is grounded in the foundational norms of respect for persons and beneficence. The right to control sensitive personal information about one's self, including one's private health information, is essential for our ability to maintain a personal sphere of sovereignty where we can govern ourselves effectively (i.e., autonomy), as well as crucial for our wider well-being, given the harm that can occur (dignitary or tangible) when sensitive personal information is taken, used, or shared without our consent.

In the context of social media recruitment, respect for privacy is especially important given the amount of personal information available online and the ease with which it can be accessed. Of course, much of the personal information available online has been *voluntarily* made public. In light of the seemingly "public" nature of this information, it may seem counterintuitive to claim substantial privacy interests. Typically, however, this information has not been shared by social media users for the advancement of generalizable knowledge, or even health purposes, but for social connectivity and personal expression. Moreover, perceptions of whether a venue is public or private may vary (Taylor et al. 2014). Posting material for social networking purposes, often within limited public communities, is different than intending for it to be available to the public in general or researchers in particular. In addition, empirical research has shown that social media users often lack knowledge of how to manage privacy settings and fail to grasp the full extent to which they render information shared over social media publicly available (Boyd 2010; Madden et al. 2013). This may result in a 'disinhibition effect' (Suler 2004; Swirsky et al. 2014) that leads

social media users to act in ways that they would find embarrassing and avoid if they knew the public or researchers were observing. For example, a social media user, not realizing that her privacy settings permit people other than her family and friends to see her posts, may describe intimate and vulnerable details of her experience with an illness that she would not want the public to see. In general, social media users may not comprehend the range of possible uses, risks, and harms of posting potentially sensitive personal information online (Parsi & Elster 2014; Taddicken 2013).

Because of this, investigators should handle personal information responsibly, even if it has already been made widely available, by minimizing the chances of individuals suffering embarrassment, loss of dignity or other harms due to social media recruitment methods. Investigators should never disclose sensitive information to others without the participant's explicit permission, or engage in online interactions that would allow others to infer sensitive information about participants or potential participants, even if that information has already been made publicly available in a different context.

In addition to considerations of privacy, researchers have an obligation to be mindful of the values, mores, and potential vulnerabilities of those they approach on social media (Gyure et al. 2014). It is possible to be respectful of privacy but nonetheless approach and communicate with different online communities in ways that are offensive or insufficiently sensitive to their condition. While researchers have similar obligations in off-line recruitment, the quickness and ease of online communication, the physical distance between researchers and investigators during online interactions, and the fact that many social media users may not expect to be approached by researchers over social media, make sensitivity to the interests and vulnerabilities of potential participants particularly important when recruiting over social media.

2.2.2. Transparency—The second salient ethical consideration in the context of social media recruitment is investigator transparency. The importance of transparency is grounded primarily in respect for persons, which, outside of exceptional circumstances, demands investigator truthfulness and honesty when interacting with research volunteers. Transparency also serves a dual function by promoting public trust in the research enterprise, which is needed for research to flourish.[5]

Transparency requires investigators engaged in recruitment activities to be truthful and honest when describing the aims, details, risks, and benefits of studies. In the context of social media recruitment the demand for transparency has further implications. The first stems from the fact that certain social media venues, such as online patient support groups, may require users of the site to have certain characteristics as a condition of joining and participation. An online patient support group for breast cancer survivors, for example, may require members to actually be breast cancer survivors themselves, or to be a close family member of a breast cancer survivor, in order to join the site. Since investigators may lack the relevant characteristics, these sites may often be technically closed to them. Transparency in

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[5]The federal regulations do permit research involving deception under certain conditions, but even in these situations the value of the research should be weighed against the possible deleterious effects on public trust and whether the research can be done using other, non-deceptive methods.

this situation requires investigators to avoid deception and refrain from fabricating online identities to gain access to these online communities, instead seeking access through alternative mechanisms, such as asking for explicit permission from a moderator or site administrator, as is discussed further below.

A second issue related to transparency concerns the obligations of investigators to proactively disclose their presence on social media when collecting information for recruitment purposes. Such information gathering can often be done relatively easily and without the knowledge of social media users, but there is a distinctive concern about whether activity of this sort may be insufficiently respectful of social media users —counting as cases of researchers 'creeping' or 'lurking' on a site where users reasonably expect that such activity will not occur and to which social media users could justifiably object. The question is whether, or under what conditions, investigators must alert social media users to their presence and purpose when viewing and collecting the personal information of strangers.

In our view the answer to this question depends largely on whether the site is reasonably viewed as a public or private space. The more public a social media venue is—that is, the fewer restrictions there are on who may join, and the easier it is for one to join without providing personal or identifying information—the less of a reasonable expectation of privacy users of the site have, and the less of an obligation investigators have to proactively disclose their presence. That said, we think it wise for investigators to err on the side of caution in this context. Even if social media users do not have a right that investigators proactively announce their presence in all contexts, the perception of researchers 'creeping' or 'lurking' may damage public perception and trust in ways that hinder recruitment and set back the progress of research more generally.

3. Cases

In this section we provide concrete illustrations of respect for privacy and investigator transparency, and our approach to evaluating social media recruitment generally, by considering several cases. The cases are intended to highlight both the methodology we recommend as well as how to bring the substantive ethical considerations just discussed to bear on social media recruitment.

Example 1

Investigator A wishes to recruit from a Facebook cancer patient support group to increase enrollment for her clinical trial, which holds the prospect of direct benefit for participants. The Facebook support group is 'open,' that is, there are no restrictions to joining the support group, no registration, no requirement to post certain minimal information, and no assumption of privacy or that all members online are afflicted with cancer. Anyone, including the research team, can identify and contact members of the group through it. Some members of the IRB wonder whether contacting people in this way would be ethically advisable, given that the group is formed around a disease category and not specifically geared toward clinical research, and that members of the group are likely to be vulnerable and may feel embarrassed, stigmatized, or alienated by recruitment advances.

The methodology we advocate first instructs us to find a more familiar off-line variant of this situation, such as a physician-investigator in a clinical setting attending an open oncology patient support group in order to make members aware of the opportunity to participate in a trial. In the latter situation, an IRB might appropriately advise the investigator to seek permission to attend the support group in order to protect patient privacy and preserve trust. Indeed, some online group settings have a moderator from whom permission may be sought. However, in at least some cases (e.g., some Facebook groups) there is no identifiable moderator from whom to seek permission. Further, in online settings such groups are often less personal and intimate, and less continuous; the nature of the group is more fluid and individuals can easily choose not to respond, unlike at in-person support groups where the person is physically present and may feel compelled to respond. These differences might justify fewer or less stringent restrictions from the IRB in the online variant. The IRB might, for example, recommend that investigators access the group through a moderator, if available, without explicitly requiring it. Or they might require the investigator to record any negative comments or information shared from Facebook members, tabulate that information, and report back to the IRB at continuing review or earlier.

In terms of substantive ethical considerations, transparency dictates that investigators be forthright that they are accessing the group in their capacity as researchers, not patients, as well as about the aim and details of the study, its risks and benefits, and so on. With respect to privacy, investigators should protect the personal information of the site's members. They should refrain from disclosing anything that would allow personal health information to be inferred about members of the group, including the fact that they are in or are eligible for the research in question, even if those individuals choose to disclose this information in certain contexts.

With respect to the concern about whether recruitment overtures would be sufficiently sensitive to this population, some members of the site may indeed feel annoyed or embarrassed by recruitment advances. But this by itself does not make recruitment unethical. The important question is whether user annoyance is based on a reasonable expectation that would be violated by the recruitment activity. The answer to this question may vary from case-to-case. One way for social media users to have reasonable expectations is for a website policy to make clear that the site is to be used expressly and *only* for purposes that do not include recruitment or research. But this is not the only way. Some types of recruitment overtures might be so lacking in tact or taste as to conflict with common and reasonable expectations in society at large, even if no website policy prohibits them. For example, approaching a Black Lives Matter Facebook group about a study on race and IQ, or a support group for parents of recently deceased young children about the effects of family tragedy on divorce rates, may conflict with widespread and reasonable norms of propriety and decency and violate reasonable expectations of these users.

That said, we think that such cases are rare, even when the people approached are sick or the situation is sensitive. In particular, while recruiting over a Facebook page for cancer sufferers requires sensitivity, it does not, we would argue, demand that researchers forego all contact with the group but rather that they be transparent, respectful, and sympathetic to their circumstances and possible suffering, making sure potential participants understand

that they will be allowed to accept or reject the offer freely, without pressure or undue influence from the research team. It is also important that, while some members of this group may feel embarrassed, stigmatized, or upset by recruitment advances, others may welcome the opportunity to participate in clinical research that can improve treatment and indeed holds the prospect of direct benefit for them.

Example 2

Investigator B wishes to use online 'banner ads' to deliver customized messages for specific individuals or groups based on their online activity, to increase targeted recruitment for his clinical trial. In the first instance, he wishes to place banner ads on a Facebook media group for expectant mothers. In the second instance, he wishes to use banner ads to deliver *customized* online messages for specific individuals or subgroups of individuals based on their search and browsing history, online profile information, and the like.

Methodologically, the first step is to ask whether and how these examples differ from the familiar practice of strategically placing flyers in physical spaces likely to be frequented by the potential study population (e.g., placing flyers for a study on depression in pregnancy in obstetrical offices). One difference is that the social media site is, while the obstetrical office is not, tracking and keeping a record of who looks at the ad or expresses interest in it. Does this difference demand greater IRB scrutiny? We would argue that the answer is a qualified 'No.' Having one's response to online ads collected and tracked is a feature of social media use *generally*. So long as the tracking and data mining activities of a site (what will be tracked, by whom, for what purpose, and so on) are publicly disclosed to potential users before they agree to join, which they typically will be as part of the 'terms of service,' people concerned about such activities can make informed decisions about whether to join.. That said, if the research team intends to track responses to their ad in ways that would not normally occur over Facebook, the IRB would have an obligation to review the risks associated with this form of tracking and, if appropriate, ensure participant protections are in place prior to the initiation of the research (which protections may include additional notification to the participant), since these risks would now exceed the background risks associated with social media use generally.[6]

A second cluster of differences arises for using customized banner ads to target individual pregnant women, given that these ads utilize personal online activity and search history in ways that placing a poster in an obstetrical clinic does not. The main concern with using customized banner ads is whether they can be employed by researchers in ways that are sufficiently respectful of privacy. However, the personal search information on which these ads are based is part of an algorithm used by the site or advertising company and is generally not shared with investigators directly. Because of this, the use of banner ads will typically not involve additional research risks for potential participants and indeed will be analogous to other off-line recruitment strategies, such as the growing use of algorithms to scan

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[6]We acknowledge that researchers have good reason to familiarize themselves with the privacy policy and terms of use of social media platforms, both to evaluate whether the proposed research coheres with a site's terms of service (see below, Section 4.1) as well as to ensure that the site will not use the data it collects from tracking responses to recruitment ads in ways that violate the Belmont principles. If there is evidence of particular social media platforms failing to respect the rights of its users or acting with blatant disregard for their interests, investigators have strong ethical reasons to avoid using those sites for research purposes.

medical records to identify patients who may be eligible for particular studies. So long as the algorithms on which online banner ads are based comply with applicable law, and investigators receive none of the information used to target individuals, they should be evaluated in the same way as more familiar off-line strategies. In other words, the IRB should affirm that no information relating to an individual's online activity will be collected and retained by the investigator, and that the language of the banner ad proposed is appropriate prior to approval.

A final possible difference is that some people may find the targeting of individual pregnant women via customized banner ads "creepy," or "creepier" than the targeting of pregnant women generally at an obstetrical office. It is doubtful that the mere perception of creepiness has intrinsic ethical weight or would demand greater protection for social media users. Nonetheless, it may lead to negative public sentiment and erode public trust in the research enterprise—which investigators and IRBs certainly have reason to avoid. That said, while the perceived creepiness of customized research ads and their relation to public trust are empirical questions, it seems to us that the widespread (and still growing) popularity of social media platforms—despite the fact that targeting of various types is prevalent over social media, and perceived by some as 'creepy'—suggests that the risk of online targeted ads significantly undermining public trust is relatively low.

If, as we have argued, the differences just discussed do not give rise to greater research risks in the online scenarios, the IRB should review them using customary norms and methods. For example, if placing posters in an obstetrician office requires permission of the doctor, which it presumably would, then posting an advertisement on the website might require permission of a moderator or other authority connected with the site.

Example 3

Investigator C is a clinical investigator conducting HIV research. To expedite enrollment, he considers using a location-based social and dating application directed towards gay and bisexual men. The platform's terms of service put no restrictions on who may or may not join, and are silent on whether the application may be used for research purposes, neither prohibiting nor expressly permitting it. Investigator C downloads the application to his smartphone, where he creates a profile that gives him access to information from other users, and observes that User M has a profile identifying him as age 29, gay, HIV+, and living in zip code 77777. This information suggests that User M may satisfy the eligibility criteria for Investigator C's clinical trial. Investigator C wonders if it would be permissible for him to contact User M to see if he is interested in enrolling in the protocol.

The first thing we should ask is whether targeting users of this application differs from other methods of seeking out the relevant population, such as, for instance, approaching individuals leaving a bar frequented by gay men. One way these two activities may differ is in the degree of certainty investigators have about whether the individuals targeted are in fact HIV+ and meet the inclusion criteria for the study. In the example above, User M has self-identified as HIV+ on his application profile, but presumably investigators recruiting outside a gay bar will typically not have knowledge of the HIV status of the people they approach. Whether there is knowledge of disease status matters ethically. Users of the application who

do not self-identify as HIV+ could legitimately take offense with a researcher who assumed that they were HIV+ simply because they are using the application, as could individuals targeted for an HIV study merely on the basis of attending an establishment frequented by gay men. Could a user of the application who self-identifies as HIV+ on their profile page, as in the original example, reasonably take offense in the same way?

It could be argued that, in some cases at least, the willingness of users to disclose their HIV status or other sensitive health information may be based on an assumption that the site is restricted to romantic uses. Individuals may be willing to disclose their HIV status to potential dates, given that this is the ethical thing to do, but hesitant or unwilling to disclose it on the application if they knew researchers would also see it. If so, Investigator C might be seen as taking advantage of a context-specific willingness to disclose highly personal information in order to use that information in ways not intended by the user and to which they might object.

The weight of this objection depends in part on further details about the aim and accepted use of the specific application and whether users are in fact justified in thinking that only potential romantic partners will view their profile. Since the site requires users to disclose information and create a profile before gaining access to the profiles of others, users are reasonable to expect that there will be some limitations on who views their information and the application may not be considered as an entirely public space. If the application is *exclusively* advertised and used as a *romantic* dating service only, users may have a reasonable expectation that researchers will not view their profile. In that case researchers would have some reason (not necessarily decisive) to avoid using the site for recruitment purposes, which would need to be weighed against the value of the research and the prospects for seeing it to completion using other recruitment strategies when determining the overall ethical status of the activity.

If, on the other hand, the site is not restricted (in policy or practice) to romantic interactions —if users tend to encounter co-workers, neighbors, people who are just curious, and so on, not all of whom are looking for dates with the user—the objection is much less concerning. In many ways, researchers, who have ethical obligations not to share the user's personal health information outside the context of research, are *less* threatening to the user's privacy and interests than others to whom the user may reveal information about himself over such a platform. Perhaps more importantly, if the application is not restricted to romantic purposes, users who are concerned about their health information being viewed by people other than potential dates may easily choose not to disclose their HIV status in their profile but instead do so only in the midst of a conversation initiated by another user whose romantic intentions are clear.

In any situation, the principle of transparency would require Investigator C to make it clear to users of the application from the start that he is contacting them for the purpose of research, rather than for social reasons. Since the primary purpose of the application is to facilitate social interaction (whether romantic or not), users of the platform might justifiably feel deceived or wronged if the research team were to approach them under the pretense of social reasons only later to disclose their underlying intent of offering them participation in

the study. Additionally, the application profile created by Investigator C should be accurate and not misleading.

Thus, while the objection reveals how context-sensitive evaluation of social media recruitment can be, and reinforces the need for IRBs to be sensitive and discerning in their application of privacy norms, it does not, we would argue, necessarily show that Investigator C's proposed recruitment technique is unethical. So long as users do not have a valid expectation that researchers will not view their profile, and so long as researchers treat personal information accessed over the application discreetly and confidentially, this sort of recruitment activity can be ethically acceptable.

As these examples show, there will typically be a good deal of overlap between social media recruitment techniques and their off-line analogues. There are, however, several aspects of social media recruitment that are relatively unique to it and that deserve special attention. In the final section of this article, we identify these aspects and analyze them in terms of their ethical implications.

4. Potentially unfamiliar aspects of social media recruitment

Despite the general similarities to traditional recruitment methods, there are several aspects of social media recruitment that are relatively novel and likely to be unfamiliar to investigators and IRBs. In this final section we conclude by recommending concrete guidance on the ethical questions raised by three issues in particular: (i) website policies and 'terms of use,' (ii) recruiting from the social networks of current or potential participants, and (iii) managing online communication from and between participants.

4.1. Website policies or 'terms of use'

The first relatively novel aspect of social media recruitment stems from the existence of website policies or 'terms of use' to which users may be asked to agree before entering a site, and to which they may be required to comply while using it, at the risk of being removed from the site and/or subject to legal consequences. Terms of use state the rules of the website on a range of possible issues, including what types of interactions are expected and tolerated on the site, how personal information shared over the site may be used, and who will have access to that information and for what purposes, among other contractual expectations. The existence of these policies demands consideration of what weight to afford them in determining what is and is not acceptable research activity. Because one function of a site's 'terms of use' may be to establish legal expectations and potential liability, it will often be important for investigators and IRBs to work together with institutional legal counsel when deliberating over ambiguous or difficult cases. Here we will leave the legal issues aside and focus specifically on the ethical issues associated with terms of use.

Terms of use establish reasonable expectations among users of different sites that others have reason to honor. If, for example, a website's terms of use require individuals to agree to refrain from certain online behaviors as a condition of using the site, users of the site can reasonably expect other users to refrain from the prohibited behaviors, and for the website to enforce its policies in cases of breach. Because of this, there should typically be a

presumption in favor of researchers complying with terms of use. On occasion, however, there may be countervailing considerations, such as whether a moderator is willing to grant an exception, the site's own behaviors and attitudes toward its stated terms of use in practice, and more generally whether there are benefits that can outweigh the risks involved with violating terms of use in particular cases.

Imagine, for example, that investigator D wishes to recruit over a patient support site, but the stated 'terms of use' restrict access to 'Patients and Friends and Family only.' However, a section of the website features prominent navigation (e.g., a dropdown panel or caption heading) for 'Emerging and Experimental Therapies and Trials.' In this part of the site there are numerous postings from researchers offering enrollment to members of the site, and archived posts clearly indicate that it is a well-traveled, active area. Investigator D proposes to advertise for the study in this area of the site. The study is likely to yield significant social value and Investigator D anticipates difficulty meeting recruitment targets by other means.

In all situations, we recommend that as part of the protocol submission, investigators either certify compliance with the terms of use on the sites they wish to use for recruitment *or* alert the IRB if their proposed recruitment techniques fail to comply with the relevant terms of use (or if it is ambiguous whether it complies with them). In this case, then, Investigator D should begin by telling the IRB that the proposed recruitment strategy is in conflict with the site's explicit terms. If Investigator D nonetheless wishes to pursue the strategy, he should make the case that the situation is sufficiently compelling or that the benefits of the recruitment strategy outweigh the risks, here noting that the website itself is not in compliance with its own terms of use, that recruitment via other avenues is likely to be slow or ineffective, and that the study may provide significant benefit. The IRB should then determine next steps. These might include requiring the investigator to contact the moderator of the website (if one exists) to seek an exception to its stated policies, which is the ideal outcome. Alternatively, depending on the comfort level and with input from institutional counsel, the IRB may decide that the situation is sufficiently compelling to justify approving the strategy in the absence of an explicit exception.

A possible ethical concern with approving recruitment strategies that conflict with published terms of use is the lack of respect for the site itself, or the owner(s) of the site. However, such considerations are not within the purview of IRBs: the mission of the IRB is to protect the rights and interests of research participants.[7] Since the site or site's owners are not research participants (or potential participants), it is questionable whether IRBs should refuse to approve strategies merely on the grounds that they do not show sufficient consideration for sites or site owners, rather than research participants or potential participants. This is especially the case when complying with the terms of use yields no increase in participant protection and indeed denies individuals the chance to participate in potentially beneficial research.

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[7]Respect for the stated terms of use of the site is, however, within the purview of the institution or sponsor of the research, as discussed below.

That said, in these cases, the institution sponsoring the research, rather than the IRB per se, may have reason to respect the site, and attend to the terms of use, which would need to be taken into account in the final analysis and judgment. This differentiation of responsibility supports obtaining institutional guidance and counsel in these cases. Additionally, there is the possibility that a website user could complain about unauthorized recruitment activity that could result in the researcher being banned from the site and have negative consequences for recruitment, which should also be considered by the investigator and IRB. In our view, however, these considerations do not support a categorical prohibition against IRB approval of recruitment techniques that conflict with stated terms of use.

4.2. Recruiting via the networks of others

The second relatively novel aspect of social media recruitment stems from the interconnected nature of social media. One key feature of social media sites is the networking of social media users with 'friends,' 'followers,' and the like. In many cases these networks can be accessed with relative ease, particularly when an initial participant was recruited using social media (but even if not), and networked individuals may share characteristics relevant for study eligibility. There are, however, risks. Most importantly, this approach risks allowing a participant's networked 'friends' and 'followers' to infer protected and sensitive information about them, including their status as research participants or their eligibility for the research—information these individuals have a moral or legal right to keep private. Because of this, investigators and IRBs must be especially attentive to protect the privacy of current or potential participants when considering recruiting via their networks.

Indeed our view is that IRBs should require investigators either to obtain authorization from current or potential research participants before using their online network for recruitment purposes, or to enlist current or potential participants to approach members of their network directly on the research team's behalf. Exceptions to this requirement will be warranted, however, in situations where the investigator independently identifies the relevant individuals for study recruitment *without using* the online network of the current or potential participant. What requires someone's permission, in other words, is not merely recruiting their networked 'friends' or 'followers' for research—people do not generally hold a right to control who may and who may not be offered the chance to participate in research—but rather that their networked 'friends' or 'followers' are being identified and targeted *using their network*.

To illustrate, imagine that researchers have successfully recruited Participant E for a study involving drug use in the LGBTQ community, and now wish to use her social media network to recruit other participants for the same study. Participant E often frequents a LGBTQ bar where there is known drug use, and she sometimes posts pictures of herself and her friends at the bar on Facebook. The researchers want to use this information to contact the friends tagged in one of Participant E's photos and offer them the chance to participate in the study.

In this case the research team has a strong obligation not to disclose Participant E's sensitive personal information to members of her online network, such as Participant E's current enrollment in the research protocol. Because of this, the IRB should require the research

team to obtain Participant E's permission before approaching her friends for recruitment (or potentially to enlist Participant E to approach them herself on the research team's behalf.) Suppose, however, that the 'friend' sought for recruitment is also independently referred to the study by her primary care physician. In that case, the IRB should allow the research team to pursue enrollment of this individual without seeking Participant E's permission. In other words, the mere presence of a potential participant in another current or potential participant's social media network is not itself a barrier to recruiting that individual. The key issue is whether the social media network is directly used for recruitment purposes, or whether recruitment occurs by other legitimate means.

4.3. Online participant communication

The third potentially unfamiliar aspect of social media recruitment stems from the possibility of online communication from and between research participants. Social media decreases barriers to connectivity and can dramatically extend the prevalence and reach of communication between researchers and study participants, as well as between study participants (and potential participants) themselves. This is possible even when social media is not utilized for recruitment, but may be even more likely when it is.

Online communication may in some cases have benefits, such as when participants share their positive experiences online in ways that promote positive public perception of research and enrollment into particular studies. But there are also risks to increased participant communication. First, participants who post detailed online descriptions of their experience may jeopardize the scientific integrity of the trial by including information that threatens to un-blind themselves, other participants, or the research team. This may occur, for example, when different participants describe in-detail the interventions they are receiving or how they feel or react to investigational agents, and speculate online about what arm of the trial they are in (Glickman et al. 2012; Marcus 2014). Second, participants posting explicitly incorrect information about the trial can undermine the understanding of other participants (and potential participants). Similarly, participants portraying their experiences in an unduly negative light may harm study recruitment and retention and thereby introduce selection bias into the trial. Finally, participants reporting their experiences with certain drugs or devices may unjustifiably influence the public perception and worth of these products (Robins 2015).

The options of investigators for dealing with these types of communication are limited, given that they have no authority to control participant communications or expression short of nondisclosure agreements or termination from the study, both of which are undesirable for a variety of reasons. In our view the best approach is to take steps to educate participants of the risks posed by certain social media communications to the integrity of the study. This might involve the development of educational materials explaining how social media communications may jeopardize the integrity of the trial, or a specific request to each participant to refrain from communications about the trial that could result in un-blinding or misperception.[8] Investigators may also wish to develop a communication plan for addressing

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[8]Such as those developed by the Center for Information and Study on Clinical Research Participation, here: https://www.ciscrp.org/primer/. See also McNair.

these risks, which could identify triggers (e.g., participant speculation on social media about which arm they are in) for interventions from the research team (e.g., corrections of misinformation or reminders about risks of un-blinding). While investigators do not, in our view, have an affirmative obligation to search for ill-advised online posts from participants, they do have an obligation to take steps to correct misinformation and ensure the integrity of the study, when such communications are brought to their attention.

Imagine, for example, that investigator F comes across a Twitter post related to migraines and finds that participants in his study are providing specific health information to others based on their experience in the trial, and incentivizing others to join (e.g. "Currently doing a #migraine study, this #Lupron is great. Join this study it pays and it works! #clinicaltrial"). A tweet of this nature may influence individuals to enroll on the basis of expectation of medical relief, or to misrepresent themselves in order to appear eligible for the trial and receive compensation. It may also threaten to un-blind the research team or other participants. When the integrity of a trial is jeopardized by the dissemination of misleading information, investigators and research institutions have a strong interest in correcting it. In such cases the investigator should post a reminder that the trial is in progress and that this type of speculation can damage the integrity of the trial. Such communication could be part of the IRB-approved communications plan, or may require an amendment to authorize this and similar communications during the trial.

5. Conclusion

The prevalence and popularity of social media is only likely to grow, and with it, the appeal of using social media as a recruitment tool. In this article we have presented a non-exceptionalist methodology for assessing social media recruitment, examined respect for privacy and investigator transparency as two key norms governing social media recruitment, and analyzed three relatively novel aspects of social media recruitment. These efforts, and the appended guidance and checklists, offer important contributions to filling the gap between the growing use of social media in recruitment and the lack of regulatory guidance and bioethical literature on this topic, and will, we hope, make it easier for investigators, institutions, and IRBs to navigate the ethical and regulatory issues. While the ethically relevant differences between social media and more customary recruitment techniques should not be exaggerated, these materials can help to serve as a roadmap for its potentially unfamiliar aspects and contribute to putting social media recruitment in proper ethical perspective as a valuable recruitment tool.

Acknowledgments

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Appendix A: Investigator checklist for proposing social media recruitment

Investigators proposing to recruit via social media are advised to take the following steps:

1. Provide the IRB with a statement describing the proposed social media recruitment techniques, including:

    •   A list of the sites to be used.

    •   A description of whether recruitment will be passive and/or active.

    •   If utilizing active recruitment, a description of how potential participants will be identified and approached, and their privacy maintained.

2. Ensure that the social media recruitment strategy complies with applicable federal and state laws.

3. Provide the IRB with a statement certifying compliance (or lack of noncompliance) with the policies and terms of use of relevant websites, OR if proposed techniques **conflict** with relevant website policies and Terms of Use:

    •   Seek an exception from the website to its terms of use; provide the IRB with written documentation of the exception, if granted.

    •   Depending on IRB policy, in compelling circumstances make the case that the recruitment strategy should be allowed to proceed in the absence of an exception from the site.

4. Ensure that the proposed recruitment strategy respects all relevant ethical norms, including:

    •   Proposed recruitment does not involve deception or fabrication of online identities.

    •   Trials are accurately represented in recruitment overtures.

    •   Proposed recruitment does not involve members of research team 'lurking' or 'creeping' social media sites in ways members are unaware of.

    •   Recruitment will not involve advancements or contact that could embarrass or stigmatize potential participants.

5. If the research team intends to recruit from the online networks of current or potential study participants:

- Provide the IRB with a statement explaining this approach and describing plans to obtain consent and documentation of consent from participants before approaching members of their online networks or to invite the individual themselves to approach members of their network on the research team's behalf.

6. Consider whether a formal communication plan is needed for managing social media activities among enrolled participants, including:

- Steps to educate participants about the importance of blinding and how certain communications can jeopardize the scientific validity of a study (e.g., a section in the orientation or consent form)

- Triggers for intervention from the research team (e.g., misinformation or speculation among participants on social media that could lead to un-blinding)

- Interventions from the research team (e.g., corrections of misinformation or reminders about importance of blinding on social media)

Appendix B: IRB checklist for evaluating social media recruitment proposals

IRBs evaluating protocols that propose to recruit via social media should take the following steps:

1. Seek to normalize social media recruitment to the extent possible, drawing analogies to traditional recruitment efforts.

2. Ensure that the proposed online recruitment strategy complies with all applicable federal and state laws.

3. Check that the investigator has certified compliance (or lack of noncompliance) between recruitment techniques and policies/terms of use of relevant websites.

- If a proposed technique conflicts with website policies and terms of use, request that the investigator seek a written exception from the site, OR

- Depending on IRB policy, request a written statement from the investigator explaining why the recruitment strategy warrants approval without an explicit exception, to be evaluated by the IRB with input from institutional legal counsel.

4. Ensure that proposed social media recruitment strategies respect all relevant ethical norms, including:

- Proposed recruitment does not involve deception or fabrication of online identities

- Trials are accurately represented in recruitment overtures

- Proposed recruitment does not involve members of research team 'lurking' on social media sites in ways members are unaware of

- Recruitment will not involve advancements or contact that could embarrass or stigmatize potential participants

5. Ensure that investigators will obtain consent from current participants before they approach members of their online network for recruitment via their network or invite individuals to approach members of their network on research team's behalf.

6. Ensure that a communication plan is in place for how the research team will handle online communication from enrolled participants that threatens the integrity of study.