

# Guidelines for Using Social Media to Recruit Research Participants

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## Prepared by

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The CTSI Recruitment Center at the University of Florida seeks to assist research teams with recruitment, accrual, and retention of study participants. Every study team is encouraged to reach out to the recruitment center to discuss study needs in the concept development stage. Initial consultations are free and can be requested by completing the [consultation request form available here and on the CTSI Recruitment Center website](#). Recruitment consultations can help ensure adequate resource allocation to project needs and recruitment and accrual success.

## Introduction to Social Media for Recruiting Human Subjects to Research

This document offers general guidelines for research teams planning to use social media, which is defined as web 2.0 applications for individuals and groups to create specific profiles and pages to facilitate online interactions, to recruit human subjects into research. *Human subject* refers to a living individual about whom an investigator (whether professional or student) conducting research: Obtains information or biospecimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or biospecimens; or obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens. (45 C.F.R. §46.102(f)).<sup>23</sup>

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<sup>2</sup> Obar, J.A. and Wildman, S. (2015). Social media definition and the governance challenge: An introduction to the special issue. *Telecommunications policy*, 39(9), 745-750.

<sup>3</sup> 45 CFR 46. HHS.gov. <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html>. Content last reviewed by OHRP February 16, 2016. Accessed April 13, 2017.

These guidelines have been developed based on existing guidance and other advisory documents (e.g., [Secretary's Advisory Committee on Human Research Protections, or SACHRP; Considerations and Recommendations concerning Internet and Human Subjects Research Regulations](#); peer institution guidelines) and are intended to address foreseeable risks of using social media to recruit human subjects into research studies.

These guidelines are not intended to address the use of social media as a venue for conducting research (e.g., collecting data about or observing online environments, incorporating social media into an intervention, data mining from social media sites); such activities are reviewed on a case-by-case basis by the IRB.

### **Role of the IRB in Study Subject Recruitment**

Per federal regulations, the IRB must review and approve the content of any activity intended to recruit study subjects. Recruitment materials are considered an extension of the informed consent and thus, under IRB jurisdiction. The IRB must approve any recruitment documents which could include any social media recruitment content (e.g., content of ads or posts, methods of communication, communication scripts, frequency of messaging) prior to proceeding and implementing social media for study subject recruitment. The UF IRB's investigator guidelines for the text of recruitment materials address a number of related issues ([click here to access guidance for Advertising for Research Subjects](#)<sup>4</sup>). Research teams are encouraged to refer to these documents prior to submitting their protocols and to contact the IRB office if they have specific questions not addressed in these guidelines. The IRB is also charged by the University to ensure investigators follow University regulations on study recruitment. Social media channels used in research recruitment (i.e., where and on which social media sites the recruitment materials appear) are not under the IRB jurisdiction.

### **Compliance with Social Media Terms of Use**

It is the responsibility of the research team, when designing a protocol, to understand the social media site terms of use, or TOU, university policies and applicable laws and to be aware of any research or recruitment-related restrictions on the social media sites through which they intend to conduct their recruitment activities. This includes a site's advertising, privacy, and prohibited content policies. Research teams are responsible for amending their recruitment plan (e.g., posts, ads) as necessary in accordance with any changes to the site's TOU that affect their recruitment.

### **Participant Privacy, Confidentiality & Data Security**

*Private information* is described as information about behavior that occurs in a context in which individuals can reasonably expect no observation or recording is taking place, and information provided by an individual for specific purposes that the individual can reasonably expect will not be made public (45 C.F.R. §46.102(f)).<sup>2</sup> If individuals intentionally post or otherwise provide information on the Internet, such information should be considered public unless existing law and the privacy policies and/or terms of use of the entity/entities receiving or hosting the information indicate that the information should be considered 'private.'<sup>5</sup>

1. It is the responsibility of the research team, when designing a protocol, to understand the various privacy and data security provisions of social media sites. Research teams must include this information in their social media management plans (see 5.a-i below) and provide this information to potential or enrolled participants as appropriate.

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<sup>4</sup> IRB Policies, Guidelines and Guidances » UF IRB » University of Florida. <http://irb.ufl.edu/index/irb-policies-guidelines-and-guidances.html>. Accessed April 13, 2017.

<sup>5</sup> hhs.gov. Attachment B: Considerations and Recommendations concerning Internet Research and Human Subjects Research Regulations, with Revisions. HHS.gov. <https://www.hhs.gov/ohrp/sachrp-committee/recommendations/2013-may-20-letter-attachment-b/index.html>. Published March 22, 2013. Accessed April 13, 2017

2. In social media or other Internet-based research settings, recruitment information can be forwarded or otherwise accessible to other individuals who may not be part of the intended participant pool. Research teams therefore should exercise caution to appropriately identify the targeted participant population and to ensure the equitable selection of participants.

### **Procedures and Considerations for Using Social Media to Recruit Participants**

The IRB will review the content of recruitment materials (i.e., the wording of recruitment flyers, posts, ads, etc.). The content of recruitment materials must be approved prior to submission to social media sites for approval and prior to posting any such materials on social media. Study teams that wish to develop study recruitment content for recruitment dissemination on a social media channel should review the following:

1. There are two overarching categories of social media recruitment.
  - a. **Interactive:** Recruitment using interactive social media posts permit users on the platform to comment, like, share, and tag others in the post on the social media site. Management of these comments depends on which method of social media recruitment research teams will be using (see 3.a-e below). The plan for managing interactive recruitment materials should be clearly delineated in the social media management plan (see 5.a-i below).
  - b. **Static:** Recruitment using static social media posts does not permit liking, commenting, sharing, or other public interactions with potential participants on the social media site. Each platform has their own policies for disabling engagement features (e.g., comments, shares) and the research team is responsible for determining whether engagement with recruitment materials will be permitted. The plan for managing static recruitment materials should be clearly delineated in the social media management plan (see 5.a-i below).
2. Permissible channels and types of social media recruiting and related considerations:

Research teams are permitted to use social media channels including accounts, pages, groups, and communities with and without opportunities for interaction (e.g., social media channels with and without commenting, linking, retweeting, sharing, etc.) for study recruitment. ***In other words, research teams are not restricted in their use of social media channels for study recruitment and may engage the channels that meet the preferences and needs of their target populations. No members of the research team should be joining a social media group or community for study recruitment purposes.***

  - a. **Interactive: Organic (non-paid, free) recruiting via public accounts, groups, pages, communities** is permitted. Social media sites permit public figures, businesses, organizations, and other entities to create an authentic and public presence online through official accounts, groups, pages, communities. Public accounts, groups, pages, communities are visible to everyone on the internet by default. Social media users can connect with these accounts, groups, pages, communities by following or becoming fans and to receive updates in their News Feed with the option to interact with posted content.
    - i. Research teams will not post to the account, page, group, community. Teams will send the IRB-approved content to the moderator, owner, social media manager via email or through a social media message and request they post the IRB-approved content to the account, page, group, community without making modifications to the approved content. Research teams should provide the manager, owner, moderator with their UF email address and phone number in case individuals have questions or comments about the study. Research teams should also provide template language for the moderator, social media manager, owner to post in response to prospective participant comments or inquires that may occur online. Privacy and other considerations related to such communication must be addressed in the recruitment plan submitted to the IRB (see 5.a-i below). The decision to allow research recruitment activities is at the discretion of the owner, moderator, manager overseeing that account, page, group, community.

- b. **Interactive: Organic (non-paid, free) recruiting via private groups, communities** is permitted. Private groups and communities are not visible to everyone on the internet. Social media users connect with private groups and communities by requesting approval from an administrator or moderator to join, or by invitation.
- i. Research teams should be aware of any site restrictions for recruiting participants via private groups or communities. If no site restrictions exist, teams should determine if the group has its own rules or requirements regarding research recruitment. If research recruitment is allowed according to the account, group, or community rules, research teams should determine if there is a moderator and request permission from that individual to – in their role as a research team member - communicate with and recruit group members.
  - ii. As described above, the IRB must approve the content of any recruitment content for use in social media recruitment. Study teams who wish to use social media channels in study recruitment should ensure the IRB has approved the text, image(s), and link associated with the recruitment materials and a copy of pre-determined responses to comments, messages to groups that will be shared with group or community members for approval. Research teams interested in this type of recruitment are encouraged to [click here to schedule a consultation with the CTSI Recruitment Center prior to submitting study materials to the IRB.](#)
  - iii. Research teams will not join or post to the private group or community. Teams will send the IRB-approved content to the group or community moderator, owner, administrator via email or through a social media message and request they post the IRB-approved content on behalf of the research team without making modifications to the approved content. Research teams should provide the manager, owner, moderator with their UF email address and phone number in case individuals have questions or comments about the study. Research teams should also provide template language for the moderator, manager, owner to post in response to prospective participant comments or inquires that may occur online. The decision to allow research recruitment activities is at the discretion of the owner, moderator, manager overseeing that account, group, or community. Privacy and other considerations related to such communication should be addressed in the recruitment plan submitted to the IRB (see 5.a-i below).
- c. **Interactive: Recruiting via paid advertising campaigns on social media** is permitted. Paid advertising campaigns use the age, gender, location, and interests to target a specific population to show study ads in users’ newsfeeds. Research teams must run paid advertising campaigns through official social media accounts that have been approved by UF and/or UF Health.<sup>6-7</sup> Investigators are responsible for all costs associated with paid advertising campaigns. Two options are available:
- i. **UF Studies account for Facebook/Meta and Instagram (streamlined submission/approval).** The CTSI Recruitment Center manages the official “UF Studies” Facebook/Meta page as a channel through which investigators can post recruitment materials to Facebook/Meta and Instagram. The CTSI Recruitment Center will facilitate the purchasing and hosting of IRB-approved paid advertising campaigns through the “UF Studies” Facebook/Meta page (also extends to Instagram) in accordance with these guidelines and UF purchasing procedures, if applicable. Research teams interested in using the UF Studies account for paid advertising campaigns are encouraged to [click here to schedule a consultation with the CTSI Recruitment Center.](#)

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<sup>6</sup> List of Accounts » UF Social Media. <https://ufhealth.org/social>. Accessed September 9, 2021.

<sup>7</sup> Social Account Directory » UF Health’s Social Media Hub. <https://social.ufhealth.org/accounts>. Accessed June 6, 2017.

- ii. **Official UF and UF Health social media accounts.** If a research team has its own official UF social media account or has received permission from a social media manager to purchase and host a paid advertising campaign through an official UF social media account maintained by a different unit on behalf of the study team, investigators may instead seek approval to purchase and host a paid recruitment campaign those accounts. Decisions on whether to allow research recruitment activities through an official account is at the discretion of the manager overseeing that account. The social media manager of that page will be responsible for launching, managing, and monitoring comments and engagement on the campaign posts. [Click on this link to learn about the institution's social media policy.](#) [Click on this link to learn more about the process for requesting and approving an official social media account within UF Health.](#)
  - d. **Interactive: Organic (non-paid, free) recruiting via private messaging** for recruitment, defined as two-way communication between a research team member and a potential research subject using private message features on social media sites (e.g., Facebook/Meta messages or messenger, Twitter or Instagram direct messages), may be considered on a case-by-case basis, and may be subject to a more extensive review. Privacy and other considerations related to such communication must be addressed in the social media recruitment plan included in the study subject recruitment plan submitted to the IRB (see 5.a-i below). Individuals who reach out to a study team member via private messaging (e.g., via Facebook/Meta Messenger to ask a question about the recruitment process or study) should be provided the contact details of the study team and directed to communicate about the study off the social media site. Research teams can review examples of this communication [by clicking here to access the social media recruitment templates.](#)
  - e. **Static: Organic (non-paid, free) recruiting via public accounts, groups, pages, communities** is permitted for research recruitment. Static social media posts do not allow for user engagement such as liking, sharing, commenting, or tagging. Each platform has their own policies for disabling engagement features (e.g., comments, shares) and the research team is responsible for determining whether engagement with recruitment materials will be permitted and used for the particular study. Privacy and other considerations related to such communication should be addressed in the social media management plan submitted to the IRB (see 5.a-i below). [Research teams should use this template to submit to the IRB.](#)
3. Social media recruitment activities must adhere to UF and UF Health social media guidelines<sup>8-9</sup>.
- a. **Personal social media accounts.** Personal social media accounts cannot be used to purchase or place initial recruitment materials for UF research studies. Members of the research team are permitted to share study recruitment materials that are posted through accounts, groups, and pages to their personal pages and accounts, without changing the post or adding comments. Personal accounts may only be used to contact account, group, page, community moderators and owners to request they post IRB-approved study content on behalf of the research team.
4. Screening prospective participants and tracking recruitment:
- a. No screening of prospective participants is permitted to occur directly on social media. All screening and data collection must occur offline (e.g., phone) or via a secure, UF-approved platform (e.g., REDCap, Qualtrics). If recruiting to a behavioral research study (e.g., survey)

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<sup>8</sup> Social Media Use, Guidelines and Policy Implications » Policies » Human Resource Services » University of Florida. <http://hr.ufl.edu/manager-resources/policies-2/social/>. Accessed April 21, 2017.

<sup>9</sup> Social Media Guidelines for UF Health » Policies and Procedures » Web Services » University of Florida Health Communications and Information Technology. <http://webservices.UFHealth.org/files/2011/07/SocialMediaGuidelines.pdf>. Accessed April 21, 2017.

- a waiver of documentation of informed consent should appear on the first page of the IRB-approved survey that the social media post links to.
- b. If any identifiable data will be collected as part of the recruitment process, investigators should describe how they plan to collect, store and use the data.
5. A social media management plan should be submitted as part of the protocol's study recruitment plan. Teams should [click here to select from social media templates](#) to develop the social media recruitment plan. The IRB will approve the content of the study recruitment materials posted on social media prior to research teams starting recruitment. The CTSI Recruitment Center is available to assist with social media recruitment planning. Teams interested in running a paid advertising campaign through the UFStudies Facebook/Meta account should [click here to schedule a consultation with the CTSI Recruitment Center](#). The social media management plan should address the following:
- a. A list of all social media channels that will be used for recruiting, including, as applicable:
    - i. List of the social media channels teams intend to use in study recruitment (e.g., Facebook/Meta, Twitter, Instagram, Reddit, etc.)
    - ii. List and links to specific social media accounts, groups, pages, communities teams intend to request to post recruitment content or purchase recruitment advertisements.

*If the UF Studies Facebook/Meta page is the only social media channel that will be used, research teams only need to address items 5a and 5c-e in their social media management plans.*
    - iii. A template message that will be sent to the owner, manager, moderator of the social media account requesting they post recruitment content and not to adjust any of the IRB-approved text.
  - b. A statement acknowledging the research team's review of and plans for adhering to the terms of use and advertising, privacy and prohibited content policies of the social media sites to be used for recruitment.
  - c. Mock-ups of all planned recruitment materials. This includes static and interactive advertisements, posts, images, banners, tags, pre-determined responses to comments, messages to groups, and any other advertising elements. Include a clear explanation of the format and placement anticipated for each advertisement. To facilitate real-time campaign optimization, it is recommended that teams submit several variations of social media content (e.g., alternate images or text) for IRB approval. Research teams can review examples and tips for developing materials [by clicking here to access the social media recruitment templates](#). Teams can also [schedule a consultation with the CTSI Recruitment Center](#) to discuss social media materials development and recruitment planning.
  - d. A description of the site where the link associated with the recruitment materials will lead (e.g., where social media users will be directed online when they click on an advertisement). Options include a link to a Qualtrics or REDCap survey or a link to a UF Health study listing page.
  - e. If applicable, targeting criteria to be used for paid advertising campaigns.
  - f. If applicable, the process for responding to group members' messages (see section 2.c above). Examples of planned responses that research teams can use to direct participant communication offline and that can be provided to the moderators, managers, page owners can be found by clicking here to access the social media recruitment [by clicking here to access the social media recruitment template](#).
  - g. If applicable, a description of how the research team plans to address privacy, data security and identity verification considerations for private messaging with potential participants on a social media site.
  - h. If applicable, a description of any identifiable data to be collected through the social media site during the recruitment process, and how such data will be stored and used.

- i. A description of which personnel will be charged with posting, monitoring and responding to recruitment-related communication on the social media site, as well as any procedures to monitor the activity of those personnel in accordance with the study protocol and UF and UF Health social media guidelines,<sup>4,5</sup> including appropriate monitoring to ensure any posts or comments involving protected health information, or PHI, or pertaining to study participation can be promptly addressed (e.g., study complaints, adverse events). For a definition of PHI and frequently asked questions, refer to the [UF Privacy Office website](#). Personnel should also ensure that social media recruitment materials are only displayed on social media sites included in their social media recruitment plan.

## Review Matrix: Research Recruitment on Social Media

Describes the level of review required for different types of study recruitment activities on social media

Levels of Review	Examples of Study Recruitment Activities
<p><b>Simple:</b> Social media recruitment channels that have been pre-vetted by the UF Privacy, Information Security and General Counsel's offices.</p>	<p>a) Posting recruitment materials through the UF Studies Facebook/Meta account and other UF and non-UF Health approved social media accounts, pages, groups with permission from the owner, moderator, or social media manager.</p> <p>b) Posting recruitment materials through non-UF pages, accounts, groups with permission from the owner, moderator, or social media manager. Purchasing and hosting paid advertising campaigns through the UF Studies Facebook/Meta account for placement on Facebook/Meta and Instagram. Teams are <a href="#">encouraged to click here on this link to schedule a consultation with the CTSI Recruitment Center</a>.</p>
<p><b>Complex:</b> Social media recruitment activities that <u>may</u> require ad hoc or ancillary reviews from the UF Privacy, Information Security and General Counsel's offices as requested by the IRB.</p>	<p>a) Purchasing and hosting paid advertising campaigns through official UF or UF Health social media accounts (the protocol submitted to IRB for approval should include a screenshot of an email or other communication).</p> <p>b) Recruiting via private messaging (i.e., direct messaging to prospective participants for recruiting without the exchange of additional communication) on a social media site (e.g. Facebook/Meta messages or messenger, Twitter direct messages, Instagram direct messages, etc.).</p> <p>c) Collection of any identifiable data through a social media site during the recruitment process.</p>

*Note: This matrix does not address the review process for protocols that use social media as a venue for conducting research (e.g., collecting data about or observing online environments, incorporating social media into an intervention, data mining from social media sites); such protocols are considered on a case-by-case basis and will require ad hoc or ancillary reviews as determined by the IRB.*