Social Media in Research

Satish Veerla
Sr. Regulatory Analyst
Human Research Protection Program

Objectives

What is Social Media Research?

- Definition
- Background

When is Social Media Research Reviewed by IRB?

- Applicability

How is Social Media Research reviewed by UTSW IRB?

- Recruitment: Advertisements
- Informed Consent
- IRB Considerations used to carry out study procedures

HRPP Policies

Background

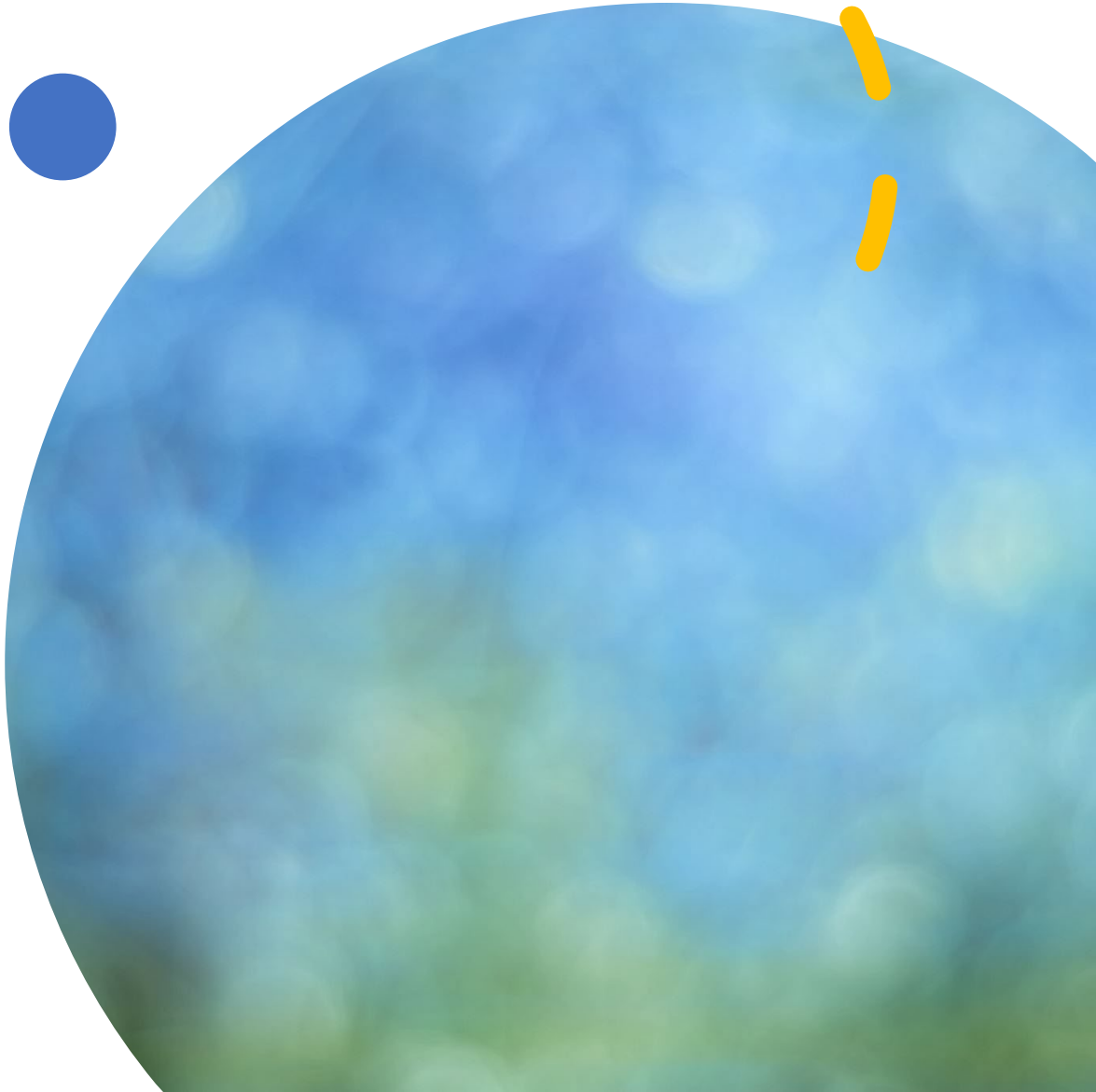
- The term “social media” refers to Internet-based modes of communication that allow users to interact with the medium (typically a website) or other users of the medium.
- Specific applications and web tools, many of which are free, are based on different, sometimes overlapping, themes and purposes, variably grouped as online communities (e.g., patient support groups, population-specific dating services); social networking (e.g., Facebook; Twitter); professional networking (e.g., LinkedIn); content production and sharing (e.g., YouTube, Tumblr, blogs); location-based services (e.g., Tinder); and others.
- Many social media web services contain one or more platforms that allow users to view one another’s networks and interact with each other in real-time. These include comment spaces, chat rooms, discussion fora, and the like.

Background

SOCIAL MEDIA CAN INCLUDE BLOGS, PODCASTS, AND TEXT MESSAGES.

SOCIAL MEDIA CAN PROVIDE UNIQUE TOOLS FOR RECRUITING STUDY PARTICIPANTS.

SOCIAL MEDIA CAN ALSO PROVIDE TOOLS TO CARRY OUT RESEARCH REMOTELY.

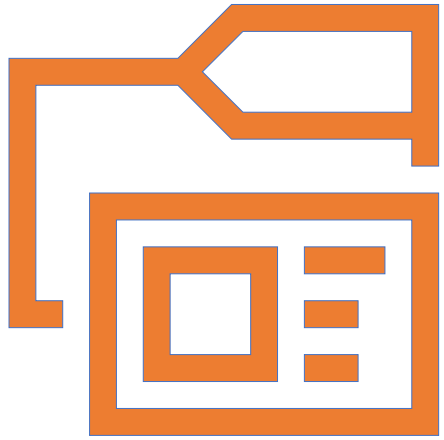


Applicability

Social Media – Internet-based applications that allow creation and exchange of user-generated content

Provide mechanisms for users to interact – chat, instant messaging, email, video, file sharing, blogging, discussion groups

Does the use of social media to carry our recruitment or research require IRB review?



Recruitment

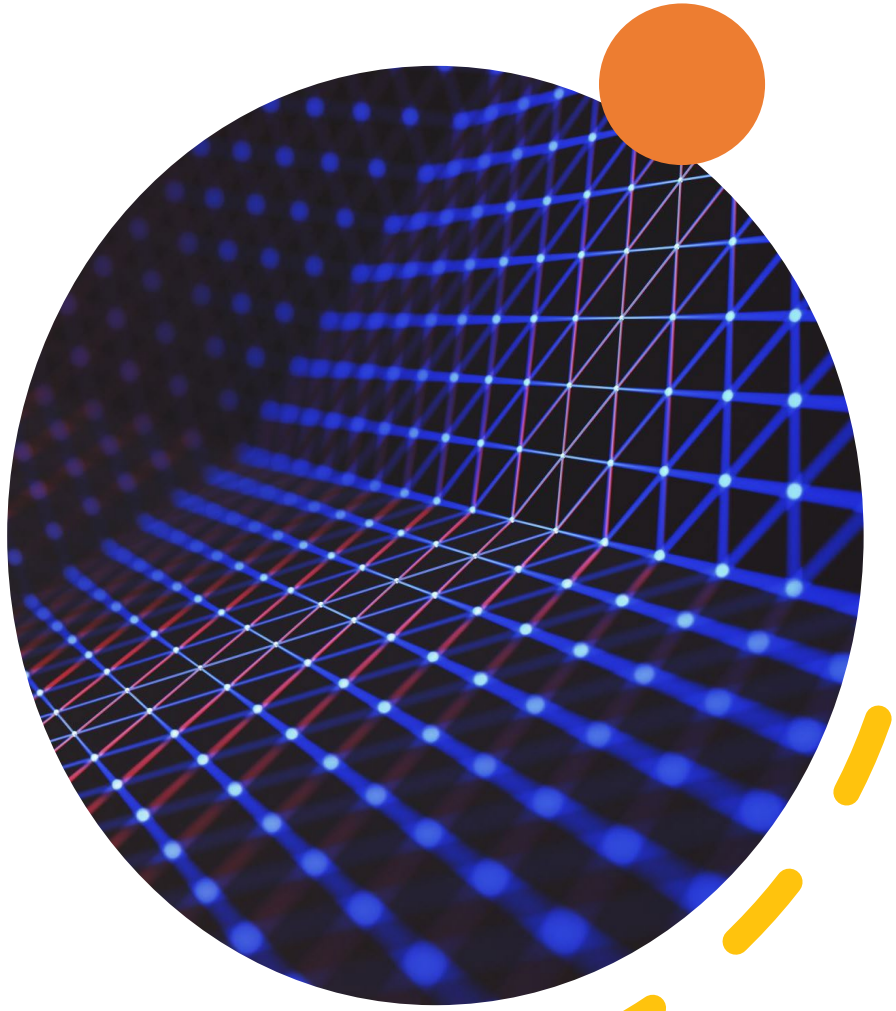
- **Social Media Use:**
  - What social media sites are used?
  - Does investigators use advertisements for their recruitment?
  - How are advertisement used for their targeted recruitment?
- **Additional safeguards for consideration:**
  - Compensation for participants
  - Routine monitoring of advertisements
  - Reviewing and reporting of privacy policies, harassment of social media tools used
  - Moderate posting on public forums
  - Prevention of fraud and mitigate fictitious account survey responses
  - Monitoring the survey links for not sharing and preventing multiple survey responses
  - Maintaining privacy and confidentiality

Advertisements

Recruiting activities are the beginning of the informed consent process.

IRB needs to review social media advertising and recruitment to ensure advertisements…

- Are not unduly coercive
- Do not promise or imply a favorable outcome or other benefits beyond what is contained in protocol
- Do not communicate that the study product is safe or effective for the purposes under investigation
- Do not make claims that the study product is known to be equivalent or superior to any other study product



Advertisements

- Do not include language indicating that regulatory authorities, such as the FDA and IRB, have approved the research
- Do not cause therapeutic misconception (e.g., modify the word “treatment” with a word that does not imply a benefit or explain that a term like “new drug” means that the study product is investigational)
- Do not promise or imply free medical treatment when the intent is only to say subjects will not be charged for participation in the investigation
- Do not emphasize the payment
- Provide information limited to that which subjects need to determine their eligibility and interest
- Do not include statements that are generally misleading

IRB review of advertisements

THE INFORMATION CONTAINED IN THE ADVERTISEMENT.

THE MODE OF ITS COMMUNICATION.

THE FINAL COPY OF PRINTED ADVERTISEMENTS.

THE FINAL AUDIO/VIDEO TAPED ADVERTISEMENTS.

ADVERTISEMENTS MAY CONTAIN THE FOLLOWING INFORMATION

- The name and address of the investigator and/or research facility;
- A summary of the purpose of the research;
- Basic eligibility criteria;
- A brief list of participation benefits, if any (e.g., a no-cost health examination);
- The time or other commitment required of the subjects;
- The name and phone number of the person to contact for further information.

Recruitment: IRB review

Review generally is required for:

- Direct Advertising – This information is presentable in many different forms and can be found on search engines, websites, Facebook, blogs, etc.:
  - Display or Banner Ads – Usually placed along the top or right-hand side of a web page
  - Rich Media Ads – Similar to display or banner ads, but have an element of interactivity, such as a roll over, scroll bar or click for more information
- Paid Search Ads – Purchased keywords relevant to the research study, ad appears on the search engine near the search results
  - Likely the information contained on the link page requires review, but not any paid search term
- In-Text Ads – Relevant keywords are selected for in-text ads, keywords are highlighted in relevant content throughout a network of sites and, as users roll over keyword, an ad pops up
  - It is the ad that pops up that likely requires review

Recruitment: IRB review

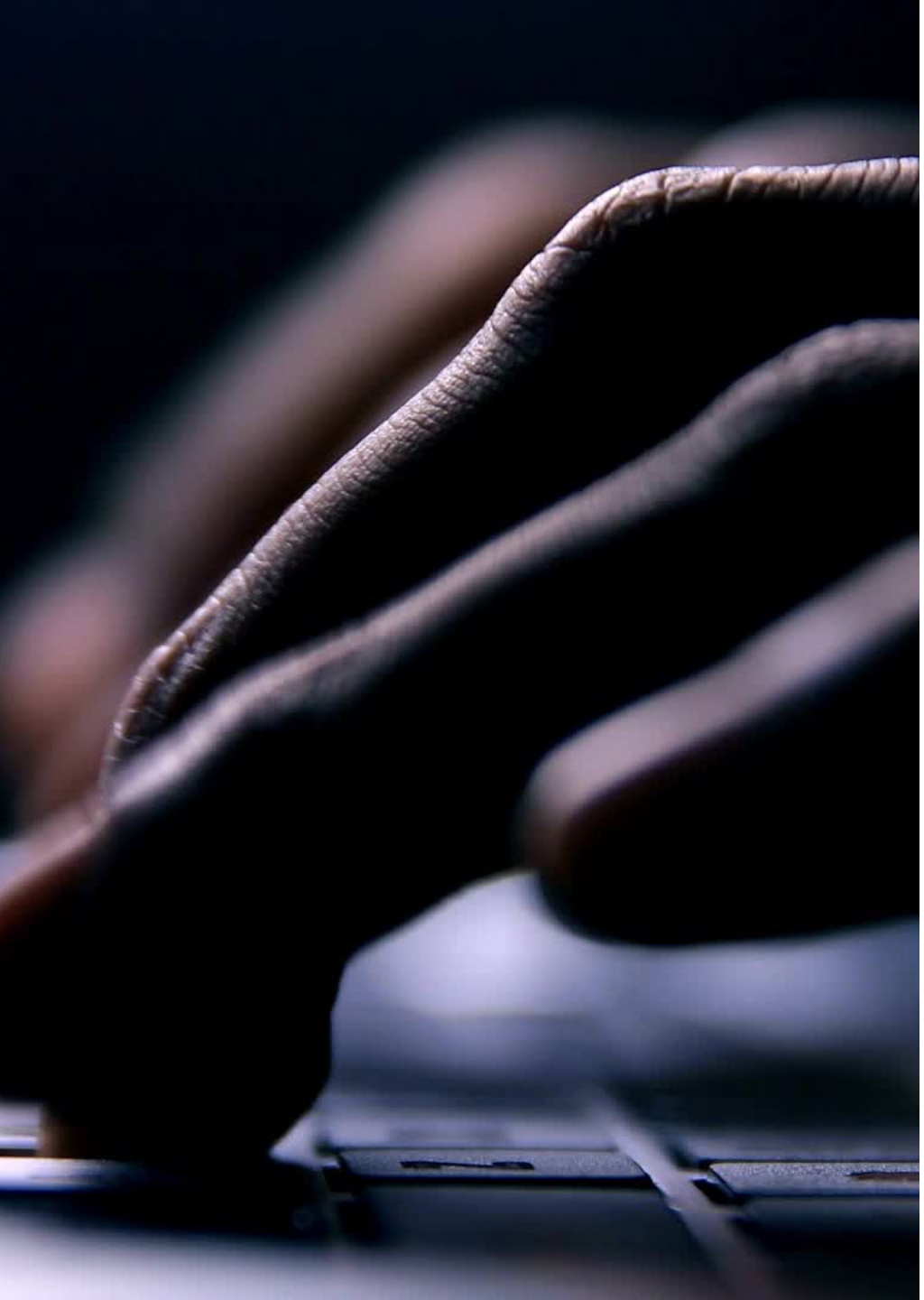
Review generally is required for:

- Social Network Ads (Ads on Social Network Pages) – Similar to paid search ads, these ads appear on social networks (Facebook, MySpace, LinkedIn) based on keyword searches by users, demographics from their profiles, geographic information from their computers, and more
  - Social networks are very targetable given the amount of information users share on their accounts
  - The ad or linked ad likely require review
- Social Network Pages – Not only ads on social network pages, but also those pages themselves setup for a specific study
  - Access or privacy settings of page?
  - Is any Protected Health Information (PHI) being recorded? Partial HIPAA Waiver required? Prescreening form?
  - Confidentiality of collected information?
- Blogs and Posts – for a specific study containing direct advertising
- Tweets and Texts containing direct advertising

Informed consent

- Researchers using social media for their studies may choose to offer research volunteer electronic informed consent (e-consent) if there is no waiver of consent.
- IRB recommendations for e-consent:
  - Language needs to be understandable for either Participant or LAR
  - Ease of access and navigation; Hyperlinks can be used
  - Option to choose for paper-based copy where participants are not well versed with the use of social media
  - Opportunity to ask questions and consider participation are necessary
  - Questions can be answered either in person, over the phone, or by video conferencing, but should be answered prior to consent.
  - Investigators should assess the understanding of the study for participants and comprehension of all elements of informed consent
  - Participants should obtain a copy of the informed consent
  - IRB's review the usability of e-consent process to ensure the ease of access and navigation for participants.
  - IRB must approve the waivers (if applicable) based on the research.
  - For vulnerable population: Prevent coercion and make provisions for re-consent (if applicable)

IRB Considerations



Private vs Public data

- Based on private information, if individuals intentionally post information on publicly accessible social media sites, such information would be considered public unless existing law or the privacy policies/terms of service of the entity hosting the information indicate otherwise.
- For example, if an investigator proposes to analyze videos available on YouTube and will not interact with the individuals who posted the information, this may not qualify as human subjects research because although the posts may be identifiable, the data have been generated from public, not private, materials.
- Essentially, if the content can be accessed by any Internet user without specific permission or authorization being required from the individual who posted the information or from the entity controlling access to the information, the post is considered “public” and therefore does not meet the “identifiable private information” criteria for human subject’s research.

Privacy and Confidentiality

Investigators requires careful consideration prior to initiating recruitment via social media platforms to ensure the protection of human subjects.

Investigators should describe how privacy protections are put in place for participants.

Investigators should describe how data is being collected, stored, accessibility, and maintained for the research where social media platform is used.

Investigators should also consider that third parties may develop novel ways to broach the security of platforms and exploit the identifiers of account holders.

Risks vs Benefit

Risk

- Third-party use of data
- Breach of confidentiality
- Exposure to malicious content;

Benefit

- Ease of recruitment;
- Increased engagement;
- Rapid sharing of information;
- Building of web-based communities;
- Web-based participation is more private than in-person participation.

HRPP Procedures to Facilitate Safe and Effective Social Media Use

- UTSW published social media guides to help investigators follow institutional privacy and security recommendations and to help them follow best practices in social media use.
- Same risk-based approach the agency uses to assure safety and effectiveness for other medium such as newspaper, fliers, posters, etc. are applied
- The researchers must adequately protect the rights, welfare and privacy of prospective subjects
  - To assure this, the researcher must include an explanation/statement in eIRB describing the privacy/confidentiality and information practices of the platform(s) that will be used to collect and store any information
  - To assure this, the researcher must obtain approval from the Social Media and Marketing team, Digital and Social Media Department via email
    - Study team must include a copy of the email in the eIRB submission
- The researcher should consider how their materials wills be used by various social media mediums. Some recruitment services can place ads on websites that the PI didn't choose; therefore, they should provide the information in a locked pdf format prior to distribution

(3)	**Recruitment Process – identifying potential subjects** Describe plans about how the population will be **identified** for the purpose of recruiting. *(e.g., database search, personal contacts, referrals, patients under the care of the research team, etc.)* *(Consider Form G (waiver of consent) and Form H, HIPAA Waiver to access (screen) PHI for identification of potential subjects)*
insert answer #3 here	
	If recruiting from more than one institution and the identification process differ - clearly describe differences here. Describe differences or insert "N/A"
(4)	**Recruitment Process – first contact** Describe how **initial contact** will be made with potential subjects (e.g., researchers will contact potential subjects or subjects will contact the researchers or make appoints to see researchers after learning of the study). Describe how those making initial contact have access to the subjects' identity and the subjects' information. *(Consider whether a Form H, HIPAA Waiver is needed to disclose PHI.)*
insert answer #4	
	If recruiting from more than one institution and the process of making initial contact differs - clearly describe differences here.

	Describe differences or insert "N/A"
(5)	**Recruitment process – setting** Describe the **setting** in which an individual will be initially approached. (e.g., private room, inpatient unit, waiting area, group setting, over internet, over phone, in public). Also, describe all interaction between the research staff and the potential subject between the time they contact the research team or vice versa and the time they sign a consent form (including pre-screening activities-see instructions for detailed guidance)
insert answer #5	
	If recruiting from more than one institution and the setting differs - clearly describe differences here. Describe differences or insert "N/A"
(6)	**Recruitment process - advertisements** Will any advertising be used? ☐ Yes (attach) ☐ No ☐ Pending (will submit an amendment after approval)
	If yes, please see HRPP Policy 4.1 Identification and Recruitment and HRPP Policy 4.2 Guidance for Advertising to Research Subjects for the requirements for advertisements. Advertisements must be reviewed and approved by the IRB prior to use.
(7)	**Consent Process** Describe the consent/assent **procedures** that will be used by the research team. • Include how: information is provided; the consent interview is conducted; the consent is signed. • Identify the study staff who will conduct the consent interview by their roles (e.g., investigator, research nurse). * If the consent process of a single subject will involve more than one member of the research team, describe how this process will be coordinated from start to finish. ** If you expect this population will have individuals likely to have diminished decision-making capacity (*not including incompetent or impaired decision making capacity*), describe the assessment process for determining whether the individual is capable of giving informed consent (i.e., evaluation criteria, time intervals) – refer to Form L for plans to assess competency.
insert answer #7	

Thank You!

- **We'd love to hear your feedback.** We invite you to provide your evaluation of Research Matters and of the Human Research Protection Program.

- Visit: https://ais.swmed.edu/redcap/surveys/?s=3PRJFCFJJW