Use of Social Media for Research with Human Subjects

NC State IRB Guidance

Social media websites (hereafter, SMWs) provide unique advantages to researchers such as innovative opportunities to collect data in a natural setting because SMWs are part of participants' daily lives; improving a study's feasibility as it can be conducted from almost any location with an internet connection; ability to recruit participant populations that are hard to reach through traditional methods; and reducing research costs

Using social media for human subjects' research can present ethics and compliance challenges, such as issues of privacy, confidentiality, the identifiable nature of data, informed consent, and user expectations. This document will provide guidance on using social media as a recruitment tool, medium for informed consent, and mode for data collection.

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Common Uses of Social Media and General Issues that Arise From Its Use

People engage in the use of social media for a multitude of reasons. The multifaceted reasons for use can complicate risks associated with research when researchers use social media as a data collection tool or when researchers use data generated from social media as research data. Below are common issues that researchers may encounter when social media is a part of a research project.

Varying Clientele

Researchers have an obligation to understand who the clientele of varying social media sites are and who is incidentally excluded or overrepresented as a result. The IRB application must discuss how the use of the social media site captures the target participant population and leads to answering the research question.

Used as a Lifeline

In some cases, social media is used by participants as their only connection or support for a particular thing. This can often be a lifeline of connection, support, etc. The researcher's presence and activity may take that away from an individual's experience or access to support. The IRB application must address the role(s) of the researcher in these scenarios, including what steps the researcher will take to mitigate the likelihood of the loss of community or support lifeline occurring.

Accidental Involvement of Minors in Research

Social media sites are environments where people can represent themselves how they deem fit, and in some cases, this may involve minors in unexpected ways. Researchers must do their due diligence to verify participant identity and exclude minors from research when minors are not the target population. The IRB application must address what steps researchers will take to mitigate the likelihood of minors accidental participation in research studies.

The GDPR

Involving people residing in the European Economic Area (EEA) in social media research, means that your study is subject to the General Data Protection Regulation (GDPR). Please refer to the NC State University IRB's guidance on the GDPR (Word document).

Bots

These days, many social media websites contain fake profiles that at first glance seem like a profile connected to a real person but instead are bots. Though this is not an IRB consideration, bot involvement will wreak havoc on the data generated from the research and the IRB recommends accounting for this issue in the study design.

Public/Private Nature of Social Media Sites

Social media websites (SMWs) contain a variety of spaces where data lives. There are three broad categories: public, private, and semi-public/semi-private.

Public Spaces and Data

Public spaces are publicly available, barrier-free group spaces where individuals can passively or actively interact with others. Data in these public spaces can be freely used, reused, and redistributed by anyone with no existing local, national, or international restrictions on access or usage.

Private Spaces and Data

Private data are data that cannot be freely used, reused, and redistributed by anyone with no existing local, national, or international restrictions on access or usage.

Semi Public/Private Spaces and Data

Semi-public/private data are data that may have some restrictions, but the restrictions vary in severity. When an IRB is making determinations regarding data use from these spaces, the following is considered:

- Participants' expectations of real and perceived privacy and expectations of how their information will be used.
- Sensitivity and the nature of the information that will be accessed and used as data for research.
- The concept of semi-private/public is especially relevant to research involving social media and taking place in online spaces.

Privacy and Confidentiality Analogies

General Life Examples

- Public: McDonalds
- Semi-public: K-5 cafeteria with no strangers
- Semi-private: A party at someone's house where they allow plus ones with no restriction
- Private: Dinner at someone's house that is invite only

Social Media Specific Examples

- Public: Open discussion on the X platform (formerly known as Twitter) in which people broadcast their opinions using a hashtag to associate their thoughts on a subject with others' thoughts on the same subject.
- Semi-public: Group with open membership where individuals can join without restriction.
- Semi-private: Group where membership criteria must be met and current access to the group is granted by current member.
- Private: Group with restricted access where only an administrator can grant access to the group or personal profile information where the owner of the profile has set privacy settings, and you

need certain permissions to access the information.

Nature of Identifiability

Data from social media is most often directly identifiable and linked to a person's real name, real identity, easily find-able direct quotes, and photos. Entering a picture, username, or direct quote etc., most likely leads to direct identification of an individual(s). This ease of re-identification and the additional possibility for triangulating other data sources with the social media data, may pose unexpected new risks to participants for which they were unaware. Please review the NC State University IRB identifiable data sets guidance (Word document).

Confidentiality, Privacy, and Site Access

User Agreements and Site Guidelines

User agreements are a combination of the intent of the website/software as well as the website's/software's explicit statements regarding privacy and confidentiality. Regardless of what the user agreement says, researchers must get consent from participants unless the study qualifies for a waiver of consent or the study is eligible for an exemption and not seeking consent can be justified. Understanding how the information on social media websites is used – and if it is shared with third parties - affects data management because of the user agreements and site guidelines.

If a username and password are required, the site is not considered public. It may be considered semi-public or semi-private based on how the creation of the username (e.g., access, ease, permission, and vetting of getting the username) occurs.

- Based on the public/private nature of the site, consent could be required to view content or use the content for research purposes. For example,
  - Can anyone sign up for the username?
  - Are there limitations about who can sign up and what are the limitations?
  - Is there a fee associated with signing up to gain access?
  - Is there verification of sign up?

  Answers to these questions will drive the determination regarding semi-public/semi-private spaces.

User Awareness

People do not often read through the user agreements and are unaware of how their information is used by the social media site including how the information is shared or sold. So when researchers are using social media sites as a "data collection tool" to collect data that would not have been otherwise generated or exist via social media, the researcher has an ethical obligation to inform the participant that by generating data on the site, they are also generating data that can be used in congruence with the site's terms but may mean that their data will be used in a manner that the users didn't expressly agree to participate in.

- In these cases, IRBs require the researcher to read through the terms and conditions of the site and identify areas that may be relevant to participant privacy and then discuss those relevant pieces of information with participants prior to their research participation. This ensures transparency and participant autonomy.
- In these cases, IRBs may require a justification for the use of the social media site as the data collection tool.

The lack of privacy and breaches of confidentiality are prevalent on social media platforms. Users are often used to nonexistent privacy and confidentiality. The normalization and desensitization around issues of privacy (about people's experience) and confidentiality (about their data) suggests that people are not fully engaged when using privacy settings or reading through user agreements.

- Despite this normalization, researchers must not exploit this aspect of participants experiences and instead model vigilance and transparency when completing research with human subjects in social media environments, including bringing to light issues of individual level privacy and confidentiality in user agreements.
- This can come in the form of the researcher stating to potential participants something like "Due to the user agreement and site features, before participating in this research we suggest that you set your privacy settings to <insert site specific information>. You can accomplish this by completing the following actions <insert information>."

User Expectations

When a person connects with someone on a social media site, they have expectations of the behavior of those they are "connected" with and how the shared information will be used.

- Researchers must be forthcoming and transparent regarding intentions of access and use of a person's social media information.
- Researcher disclosure is a critical part of the ongoing informed consent process where consent for access and use of information is permitted by the user.

Ethical issues related to trust, transparency, and relationships arise when researchers connect with or "follow" participants on social media sites.

- Connection or following participants can integrate the researcher into the participants community in some way, shape, or form and by doing so, the researcher agrees to a unarticulated social contract. This entrance, participation, and exit from the community may have effects that influence the community, including use of data to create meaning.
- The IRB suggests that researchers review the NC State University IRB's guidance for qualitative research and the IRB (Word document).

User Involvement

When the user has control over their privacy settings, they have the access to set controls to limit who can access what content. Typically, these settings involve:

- Publicly Available Settings: allowing any user (or in some cases non-users) access to the content on their profile and postings.

- Private Settings: limiting some or all profile information and posting access to online "friends" approved by the profile's owner. Privacy settings can limit access to the profile, or settings can be customized to limit access to certain profile viewers or to sections of the profile.

The public or private settings of the social media information about the participant can influence IRB review level. How the participant enacts their settings, will in turn affect whether IRB approval is required, and if so what level of review will be required.

- If the social media content is completely public and has always been public, the IRB does not regulate the use of public data unless there are other research procedures such as use of information that was once private but is now public, non-public information, or other research procedures.

- If the social media information was once private but is now public or can be considered semi-public, the IRB will regulate the research involving that information, but it will likely be eligible for exemption unless there are other research procedures or non-public information used.

- If the social media data is semi-private or private, the IRB will regulate this research and it will be reviewed at the expedited level unless there are other research procedures that require additional levels of review.

Types of Data Accessed or Generated

Text

The NC State University IRB is concerned with ease of re-identifiability of a participant regarding discussion topics, sentiments, or emotions elicited or instigated by the research via text. Text can be in forms of direct posts or comments. Direct quotes from posts can be easily re-identified without a picture or a username. Aside from others being able to likely see the participant's textual response, the textual data may also have "ownership" issues between the site itself, the participant, and NC State University (since the text will be used as research data). Sometimes these concerns can be addressed by removing the poster's name/username, redacting identifying information from the post, and not using exact quotes. However, a participant

should explicitly consent for their direct quotes, that may lead to re-identification, to be used for research publication, presentation, and sharing.

Images
The NC State University IRB is concerned with ease of identifiability of individual participants and third-party participants. Aside from others being able to likely see the participant's images from the research, it may also have "ownership" issues between the site itself, the participant, and NC State University (since the images will be used as research data). Sometimes these concerns can be addressed by blurring out personal identifiable information, location references, and individual faces from the image, especially if it will be published (e.g., a person in uniform may need their rank, name badge, or company emblem blurred). However, a participant should explicitly consent for their image, that may lead to re-identification, to be used for research publication, presentation, and sharing. Please refer to the NC State University guidance for images and recording in human subjects research (Word document).

Audio
The NC State University IRB is concerned with ease of re-identifiability from voices or other sound recordings of both primary and third-party participants. Though not as easy to re-identify an individual from voice alone, it is considered an identifying piece of information. Aside from others being able to likely hear the recorded response, the audio recorded data may also have "ownership" issues between the site itself, the participant, and NC State (since it's research data). If audio recordings will be published, voices must be dubbed to reduce the likelihood of identifying individuals recorded. However, a participant can consent for their audio recordings, that may lead to re-identification, to be used for research publication, presentation, and sharing. If the audio recordings are only used as data, the IRB recommends removing the recordings from the social media site, transcribing them, and securely deleting them from all platforms. Please refer to the NC State University guidance for images and recording in human subjects research (Word document).

Video
The NC State University IRB is concerned with identifiability from both voices and faces in the video. Aside from others being able to see and hear the video recorded response, the video recorded data may also have "ownership" issues between the site itself, the participant, and NC State (since it's research data). If video recordings will be published, voices must be dubbed, and faces must be blurred to reduce the likelihood of identifying individuals recorded. However, a participant should explicitly consent for their full recordings, that may lead to re-identification, to be used for research publication, presentation, and sharing. If the videos are only used as data, the IRB recommends removing the recordings from the social media site, transcribing them, and

securely deleting them from all platforms. Please refer to the NC State University guidance for images and recording in human subjects research (Word document).

Researcher Role in Social Media Data Access or Generation

Social Media Data as Secondary Data

This is when researchers use social media content that has already been or will be posted by the user without any influence, interaction, or intervention from the researcher. In this case, the social media information and content would be generated regardless of the research taking place (or research question being asked). Please see the NC State University IRB's guidance on secondary data (Word document).

Social Media Websites as a Tool for Primary Data Collection

This is when the researcher uses social media as a tool for collecting data. This means that the information generated on the social media platform was generated because of the researcher's influence, interaction, intervention, or manipulation of the participants' environment, and would otherwise not exist.

Observations of People Using Social Media

- Publicly available information that is not directly identifiable or unidentifiable through access, expertise, researcher role, analysis, or triangulation of data.

- Publicly available information that is identifiable and disclosure of the information responses likely do not place the subjects at risk of criminal or civic liability, or would be damaging to the subjects' financial standing, employability, or reputation.

- Publicly available information that is identifiable and disclosure of the information responses could reasonably place the subjects at risk of criminal or civic liability, or be damaging to the subjects' financial standing, employability, or reputation.

Other Modes of Data Collection

Other modes of data collection include surveys, interviews, focus groups, benign behavioral interventions and manipulation of environment, to friending or following a user.

- Data should not be collected through any social media sites chat or mail feature.

- Please review the NC State University IRB guidance on
    - Surveys (Word document)
    - Qualitative research (Word document)

    - Benign behavioral interventions (Word document)

- Manipulation of environment using social media is when a researcher manipulates a participant's online environment in some way that would possibly influence the participant's online behaviors or access to something. Manipulating a participant's environment online without their knowledge constitutes a study involving deception and all regulatory requirements must be addressed regarding studies involving deception including a debriefing process.

Risks to Participants as a Result of Research Using Social Media
When classifying data into the four categories on the public/private spectrum (e.g. public, private, semi-public, semi-private) it is not only important to consider the content, but also the context of the information you are accessing, collecting or generating.

Below are several contexts to consider when getting started, as each context poses possible risks to participants. Within each of the contexts noted, there may be some level of sensitive information that may adversely affect people during the primary data collection or from accessing and using the social media information as secondary data that will be subsequently widely spread. Because of researcher actions and access, the potential for harm to participants from the use of the information from social media, must continually be assessed to ensure individuals are not adversely affected by the information is used as data for research.

Once the context is identified but before proceeding with data collection, the IRB expects that the ethical use of the information be considered. Please refer to NC State University's IRB's guidance for risks and benefits in human subjects research (Word document).

Political Context
Information regarding politics may be emotionally charging. In certain locations with volatile political situations, participants could be endangered if comments can be linked back to individuals. In some cases, political references may be damaging, cause legal issues, life threatening issues, and as a result, the use of them may violate ethical codes of conduct.

Social Context
Some discussion topics may contain offensive or sensitive material which may adversely affect participants or associated third parties. Although privacy categories provide barriers, they are not all encompassing. In certain instances, the groups or forums may be considered a "safe space." Researchers should consider if they are infringing on a private space for the sake of observation and data collection and if that is truly necessary to answer the research question and what harms the research will cause to participants. Some individuals may be adversely affected (e.g. discouraged from posting, concerned for loss of confidentiality, exiting the group) by a researcher's

participation in, observation of, or use of the group/forum's data even if the platform's term of service allow such use. In these cases, researchers are encouraged to reflect on what should be done from an ethical perspective rather than what can be done legally.

Employment Context
Some discussion topics can lead to information being shared about a participant's behaviors, thoughts, feelings or opinions as related to their work environment, work culture, colleagues, or supervisors including issues related to employee fit. This puts the participant at additional risk related to maintaining employment or issues related to work community and promotion.

Legal Context
Legal concerns can arise regarding use of the site and its terms and conditions as well as other regulatory code. Additionally, unlawful behavior may be shared and as a result, reporting obligations of the researcher must be considered and legal ramifications of the information shared must be considered.

Breach of Confidentiality and Privacy
An individual's reasonable expectation of privacy must be taken into consideration regardless of what the terms and conditions say - there must be an assessment of user expectations. Access to social media data must be detailed and agreed upon between the researcher and participants on a regular basis. Common harms in this risk category include personal embarrassment and resource loss (e.g., voluntary disengagement from fear of being observed nonconsensually for research purposes).

Legal Considerations

- If posting on social media or use of social media is a requirement for a course, FERPA (Word document) may apply.

- If the data used for the research is about people residing in the EEA, then the GDPR (Word document) applies

- Mandatory reporting obligations of the researcher. The researcher must understand their reporting obligations that are legally or ethically required of them as a result of their multiple roles. Please refer to the NC State University IRB guidance on mandatory reporting (Word document) The researcher should explore their legally required reporting requirements and their ethical reporting requirements and discuss them in the IRB application with a plan related to their obligations. This will be taken into consideration during IRB review.

IRB Review Considerations

- Social media site used and justification for use,

- Target population and who is included/excluded.
- Informed consent, parent/guardian permission, and minor assent processes.
- Data collection methods including identifiable nature of data.
- Participants perception of privacy and activity that takes place on social media.
- Researcher transparency and training of participants around user agreements and privacy settings when data collection occurs on sites.
- Effect of researcher presence on people using the site.
- Risks and benefits to participants for being in the study.
- Data management and protection throughout the lifecycle of the data.
- If the criteria for approval (opens in a new window) are met.

Participant Recruitment

There are multiple ways to use social media for recruiting research participants. These range from one-time posts, to ads, to involvement in groups etc. Regardless of recruitment mode, if an account must be associated with the advertisement, it should be an account linked to the study, not an account from an individual researcher on the study. This promotes transparency and informed consent from the beginning of the research procedures. A researchers should not conflate their personal social media with the social media used for facilitating research.

Researchers are encouraged can use the following recruitment methods:

- Create a study specific profile and use the profile to make posts on social media or in groups etc. The post must be approved by the IRB before use for non-exempt studies.
- Purchase an ad that leads participants to information about the study. The ad must be approved by the IRB before use for non-exempt studies.
- Use a study specific profile to gain permission and access private groups to advertise the study or discuss research participation. This should be done for all types of studies, including exemptions.
    - The study specific profile must align with how potential participants gain permission to access groups, and all information posted to the group by the researcher must be transparent about their purpose and activity in the group, including how the researcher/profile will behave in the private

group.
    - Permanent posts that advertise the study must be approved by the IRB and talking points for possible interactions should be included in the IRB application for non-exempt studies.

- If a researcher wants to target individuals to be a part of the study because something about the user profile meets the target population, this is permissible. However, it must be done privately via a private message and transparently with the content of the message being upfront and respectful. The researcher cannot publicly recruit an individual participant (do not "@" a person). The recruitment message sent to the participant most likely needs to be approved by the IRB before it is used for non-exempt studies.

Consent Processes When Using Social Media for Human Subjects' Research
Participating in research is a gift that your participants give to you, the researcher, and to those who will benefit from the research. This gift is always voluntary and can only be given in the context of a full understanding of the research activities, risks, benefits, and a participant's affirmative choice.

When using social media as a medium, the researcher must consider how informed consent is obtained and documented, when it should be collected from participants recruited online, and how participants can revoke consent.

The required information for informed consent and its process is determined by target population, research design, the federal laws governing research with human subjects, and the risks associated with the research. Please refer to the NC State University IRB unit standard for seeking informed consent, minor assent, and parental permission (Word document), NC State University IRB exempt consent templates (Word document), adult participant non-exempt consent templates (Word document), and the parent/guardian non-exempt consent template (Word document).

Most consent processes are completed in person or synchronously on a virtual platform such as Zoom or WebEx, however, with secondary social media data research, researcher and participant discussing consent to research is not always possible. The absence of direct, synchronous, or in-person contact adds complications to the consent process. Three common concerns with consent in social media research include verifying identification, ensuring comprehension, and obtaining appropriate documentation when required.

- **Verification of Identity:** Adequate identity verification may in some cases be handled by the hosting survey provider. With minimal risk research exempt research, verification of identity may not be a critical issue.

- **Participant Comprehension:** Comprehension of the consent materials may be addressed by a checkbox ("I understand and agree") for low-risk research, or by mandatory quizzes as a comprehension check.

- **Documentation of Consent/Permission/Assent:** The federal ESIGN law authorizes electronic signatures in certain contexts. In other contexts, state law may control it. However, for most research at NC State University, a typed signature is acceptable.

Obtaining Informed Consent
Researchers can obtain informed consent using the encrypted Qualtrics or RedCap platforms where participants can agree to be in the study. In some cases, the research design requires an entire consent process and not just a consent form. This is usually for complex research or for research that is more than minimal risk. Components for these more complex informed consent processes commonly include:

- Screening for inclusion/exclusion criteria and ID/age verification.

- Blank consent documents that are sometimes be emailed, faxed, made available on a web site, completed using Qualtrics, or in some cases, officially signed with tools like DocuSign or Adobe before being returned to the research team as completed.

- Some consent processes include information provided in audio, video, or infographic formats which aid in the comprehension of the research activities and associated risks that participants would be assuming.

- Participants may be required to take a quiz after reviewing the consent materials where a certain comprehension score deems the participant eligible or requires re-consent.

- A designated contact for questions or additional information available to participants at all times.

- Applications such as the encrypted ZoomPro platform of NC State University have also been used to enable direct communication between researcher and participant throughout the consent process.

Obtaining Parental Permission and Minor Assent
Research with minors on social media raises regulatory concerns because of state and federal laws that govern research with minors and the difficulties with age verification and acquiring parental permission for the minor's participation.

- There are age verification software products available, which may be of use to researchers. The NC State University IRB does not maintain a list of approved software products that are licensed for researchers to use, but OIT does.

- Verification of age can take place through less formal fact-checking mechanisms embedded in the research instruments (for instance,

cross-validating multiple age and birth date questions).

- Researchers may advertise only on sites that are age limited.

- Coordinating parental permission with child assent can be difficult, and the Children's Online Privacy and Protection Act (COPPA) mandates parental permission if subjects under the age of 13 provide identifiable information to the researcher. Researchers must comply with this law if it is applicable to the study.

- The federal regulations that govern research with human subjects require minors under the age of 18 to have parent/guardian permission and minor assent unless the study qualifies for a waiver of consent or parent/guardian permission. NOTE: Opt-out processes must meet the waiver of consent or parent/guardian permission requirements.

    - Obtaining parent/guardian permission in a study that involves recruitment via social media websites provides challenges, as a minor may be able to complete the parent/guardian permission process posing online as the parent.

        - Adolescents are often more internet savvy than their parents and may find this process simple. However, this issue is not specific to research on social media platforms. Minors can and have easily forged their parent's signature using traditional paper forms. Although representing a parent's consent online by checking a box may be easier than forging a parent's handwritten signature, both methods are possible and easily achieved by a modern adolescent.

        - In these cases, the NC State University IRB will take into consideration the research design, risks to participants, varying laws, and modes of informing parents to achieve parental permission.

Waiving or Altering Consent, Parental Permission, and Assent
Only studies that require mid-level review (e.g., expedited) or convened full board review must request a waiver or alteration of consent if they want to waive or alter the consent process. In studies that use social media but also want to collect data that is subject to other laws (such as FERPA), those laws have requirements for consent or authorization that must be met.

Template Language for Applying to the IRB
Below are examples of language that you can use and apply to your study when using social media in research.

Social Media as a Sampling Frame
"The following social media sites will be used for targeting potential participants: <insert information>. These sites will be used because <insert rationale for why site(s) facilitate appropriate research recruitment targeting>. Individuals who do not meet the study's inclusion criteria <choose one: will or will not> learn about the research study through the site. <Include and fill-in-the-blank if appropriate to study: If individuals who do not meet the inclusion criteria will be able to learn about the study from the site, they will be appropriately excluded from the study with the following procedures: <insert information>.

Recruitment
Use and complete the following fill-in-the-blank paragraph(s) appropriate to your study and include them in the non-exempt IRB application:

- The following social media sites will be used when recruiting participants: <insert information>. These sites were selected because <insert scientific rationale for site selection>. The recruitment information that will be used on these sites is uploaded to the IRB application. Potential participants will receive the recruitment information by <insert information how the information will be posted – as a public post? In a special interest, membership only group?> If individuals are interested in participating, they <insert information about how they will sign up for participating – e.g., will they click a link to access an online Qualtrics/RedCap research screener or consent form? etc.>

- "The account used for recruiting participants is an account associated with this study and not a personal account. No personal accounts will be used in the recruitment of participants"

- "Participants will be made aware of the purpose of the social media account used for recruitment by the following methods: <description in account profile, username associated with account, etc.>"

- "The researchers will not reach out to individual participants via their social media sites in a public manner. For example, the researcher will not "@user" to call a user's attention to their study. Instead, researchers will identify participants and reach out to them through the following method: <insert method of communication, it cannot be public if the recruitment is at the individual level>."

Where Informed Consent/Permission/Assent will be Sought & Documented
Use and complete the following fill-in-the-blank paragraph(s) appropriate to your study and include them in your IRB application:

- **Adult Participants**: "Informed consent will be sought from participants by <describe processes that you will use to obtain informed consent>. Please see uploaded informed consent material(s). The research team for this protocol <select: is or is not> requesting a waiver of signed consent."

- **Parents/Guardians of Minors Recruited for Research**: “Permission will be sought from parents/guardians by <describe processes that you will use to obtain parental permission>. Please see uploaded informed parent/guardian permission material(s). The research team for this protocol <select: is or is not> requesting a waiver of signed parent/guardian permission.”

- **Minor Children**: “Minor assent will be sought from participants by <describe processes that you will use to obtain informed minor assent>. Please see uploaded informed minor assent material(s).”

Where a Waiver of Informed Consent/Parental Permission will be Sought

Use and complete the following fill-in-the-blank paragraph(s) appropriate to your study and include them in your IRB application:

- **Adult Participants**: The research study qualifies for a waiver of informed consent because it meets the criteria for a waiver. The research study is no more than minimal risk because <insert justification>. Waiving participants right to consent will not affect their rights and welfare because <insert justification>. The research study cannot be done without the waiver of informed consent because <insert justification>. The data about participants <select one: will or will not> be identifiable. If the data is identifiable, the research study still needs a waiver of informed consent because <insert justification>.

- **Parents/Guardians of Minors Recruited for Research:** The research study qualifies for a waiver of parental permission because it meets the criteria for a waiver. The research study is no more than minimal risk because <insert justification>. Waiving parent/guardians’ right to permit their child to participate will not affect their or their child’s rights and welfare because <insert justification>. The research study cannot be done without the waiver of parent/guardian permission because <insert justification>. The data about the minors <select one: will or will not> be identifiable. If the data is identifiable, the research study still needs a waiver of parent/guardian permission because <insert justification>.

Where an Alteration of Consent will be Sought (i.e., a study with deception)

Use and complete the following fill-in-the-blank paragraph(s) appropriate to your study and include them in your IRB application:

- **Adult Participants**: The research study will alter the consent process by <describe the deviation from normal consent practices>. The alteration of consent affects <explain which participants will be affected by the alteration of consent – all? some?>. The research study cannot be done without an alteration of consent because <provide justification>. The research study is no more than minimal risk because <insert justification>. Waiving participants

right to consent will not affect their rights and welfare because <insert justification>. The research study cannot be done without the waiver of informed consent because <insert justification>. The data about participants <select one: will or will not> be identifiable. If the data is identifiable, the research study still needs a waiver of informed consent because <insert justification>.

- **Parents/Guardians of Minors Recruited for Research:** The research study will alter the parent/guardian permission process by <describe the deviation from normal parental permission practices>. The alteration of parent/guardian permission affects <explain which parents/guardians will be affected by the alteration of consent – all? some?>. The research study cannot be done without an alteration of parent/guardian permission because <provide justification>. The research study is no more than minimal risk because <insert justification>. Altering the parent/guardians' right to permit their child to participate will not affect their or their child's rights and welfare because <insert justification>. The research study cannot be done without an alteration of parent/guardian permission because <insert justification>. The data about the minors <select one: will or will not> be identifiable. If the data is identifiable, the research study still needs a waiver of parent/guardian permission because <insert justification>.

Information to Include in Consent/Parental Permission Form
Use and complete the following fill-in-the-blank paragraph(s) appropriate to your study and include them in your IRB application:

- **Adult Participants**: The research study will collect the following public data about you from social media <list the data that will be accessed, collected, and used for the study such as user handle and public videos/images/posts/comments, etc.>. The research study will collect the following semi-public/semi-private data about you from social media <list the data that will be accessed, collected, and used for the study that is semi-public/semi-private such as a threaded group conversation, etc.>. The research study will collect the following private data about you from social media <list the data that will be accessed, collected, and used for the study that is private, such as private locked posts/videos/images, etc.>. People <select one: will or will not> be able to know that you participated in the research because <provide justification – including any manipulation/redaction of data points as a participant protection>.

- **Parents/Guardians of Minors Recruited for Research:** The research study will collect the following public data about your child from social media <list the data that will be accessed, collected, and used for the study such as user handle and public videos/images/posts/comments, etc.>. The research study will collect the following semi-public/semi-private data about your child from social media <list the data that will be accessed, collected, and used for the

study that is semi-public/semi-private such as a threaded group conversation, etc.>. The research study will collect the following private data about your child from social media <list the data that will be accessed, collected, and used for the study that is private, such as private locked posts/videos/images, etc.>. People <select one: will or will not> be able to know that your child participated in the research because <provide justification – including any manipulation/redaction of data points as a participant protection>.