Procedure Title: Internet and Social Media-Based Research

Associated Policy:	Human Research Protection Policy (OSA Policy 1.0)		
Responsible Unit:	Office of Scholarly Activity		
Created:	08/14/2023	**Executive Lead:**	Chief Research Officer
Effective:		**Revision History:**	.00 – 9/5/2023
Approved by:	Institutional Review Board		
Procedure Number:	137		
Key Words:	Internet Research; Social Media; Recruitment; Terms of Use		
Purpose:	To meet the responsibilities for protecting human subjects as issued by the Office for Human Research Protections (OHRP) requirement for individuals involved in the conduct or review of human subjects' research at institutions holding OHRP-approved Federal Wide Assurances (FWAs)		

Process:
This SOP serves to inform all agents, offices, departments, and affiliate sites of PNWU regarding unique issues and considerations when conducting internet/social media-based research with human subjects.

This SOP must be used as a guide in parallel with OSA Policy 1.0. SOPs are not intended to supersede existing institutional policies, and local, state, and federal laws and regulations.

Introduction:

The use of social media has become increasingly common both for recruiting research participants and collecting data. Generally, the term social media includes forms of electronic communication (such as websites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (such as videos). Some examples of social media include Twitter, Facebook, TikTok, and YouTube, but there are many others. The following guidance addresses what a researcher should know when recruiting or collecting data using social media.

Remember, internet and social media-based research projects are reviewed by the Institutional Review Board as any other research project. Set forth below is additional guidance to help researchers understand their responsibilities when social media is used in their research.

Responsible Parties

The Institutional Review Board (IRB) is responsible for:

- Protecting the rights and welfare of human research participants;
- Impartiality when reviewing human subject research;

- Remaining immune from pressure by the institution's administration, the investigators whose protocol are brought before it, or other professional and nonprofessional sources.

The Office of Scholarly Activity (OSA) is responsible for:

- Supporting the investigator in the development of research protocols and the source documents required for the conduct of research;
- Overseeing and providing the necessary support to the IRB;
- Monitoring compliance with this SOP;
- Posting this SOP for the PNWU community.

The Investigator is responsible for:

- Being a steward of a research environment that promotes the responsible conduct of research;
- Seeking necessary permissions and complying with internet/website terms of use;
- Protection of confidential and proprietary information;
- Ensuring compliance with the IRB-approved protocol, federal regulations, state laws, good clinical practice, and applicable FDA guidance;
- Seeking support from OSA and the IRB when questions arise.

Definitions

Please reference the Glossary for complete definitions of the following terms and additional terms not listed.

- Federal wide Assurance
- Generalizable Knowledge

1. When is Use of Social Media Not Considered Human Subjects Research Requiring IRB Review, Approval and Oversight?

Remember, under federal law, research is considered human subjects research subject to IRB review, approval and oversight when a researcher:

- 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 CFR 46.

In general, accessing public posts on social media sites such as Twitter, Facebook, public forums, etc., where the researcher is ***not*** interacting with the person who posted, and the disclosure of the data would ***not*** place the person at risk, would be considered *not* to be human subjects' research. Public posts would be those that do *not* require a login or account to access the information.

However, if accessing the information requires registering, being a member of the group, or "friending" a specific person or group, then that information is no longer considered public. In those cases, the researcher "uses, studies, analyzes or generates identifiable *private information.*" Thus, this research would also require IRB review.

The Principal Investigator must also review the terms and privacy policies of the sites they want to use. Some sites may restrict the use of the data for research. The Principal Investigator needs to understand and be familiar with the terms of service and end user license agreements of the site.

The IRB also suggests removing as much identifying information as possible when using these publicly available data to protect the privacy of the individuals. The IRB recommends that individuals not be individually identified or that the information on the individuals be combined in such a manner that the identity of the group or individuals could not be readily ascertained. It is common practice in social networking sites to use pseudonyms (sometimes referred to as avatars or personas). Personas should be treated like human subjects; it is not appropriate to identify the real person behind an online persona.

It is the responsibility of the Principal Investigator to determine whether IRB approval is needed for their research and obtain that approval as necessary. When in doubt, the Principal Investigator should contact the Office of Scholarly Activity so that the IRB can make a determination if IRB review is needed.

2. Can A Researcher Use Social Media to Recruit Participants?

Yes, but only with IRB approval. Internet-based research can provide easy access to a large number of potential participants but also raises a number of challenges and concerns regarding privacy, confidentiality and informed consent. While the federal regulations for human subjects' research do not address the unique issues raised when using the internet and social media for research and recruitment, the projects must adhere to the ethical principles found in the Belmont Report and must provide the same level of protection as any other type of research involving human participants.

A. In order to ensure compliance with regulatory obligations regarding recruitment of participants:

- The Principal Investigator needs to provide the IRB with the names of the platforms they intend to use as well as all the advertisements they plan to use on these sites.
- Principal Investigator should ensure that recruitment of individuals using the social networking site meets the criteria for equitable selection of participants and that sample selection is justified. The Principal Investigator should also be aware that in a social media or other internet-based research settings, the respondent population may not be entirely under the Principal Investigator's control, as the recruitment information can be forwarded or otherwise accessible to other individuals who may not be part of the intended participant pool. The Principal Investigator should, therefore, exercise caution to appropriately identify the target participant population as part of the survey process.
- It is the Principal Investigator's responsibility to make sure that the advertisements adhere to the rules and policies of the platform; these policies may include the maximum number of characters allowed as well as the images allowed on the platform.
- Screening of participants should not be conducted on the social media platform to protect the privacy of the potential participant.

B. Use of Amazon Mechanical Turk as recruitment venue for surveys and other studies

The use of Amazon Mechanical Turk as a recruitment method for human participant studies continues to grow. Mechanical Turk is advertised as a "marketplace for work," and individuals who take part in the activities called "HITS" on this site are referred to as "workers." The compensation for the tasks accomplished is typically very small, usually less than $1. The considerations for using this site for recruitment of participants are the same as with any human participant research. Additionally, the IRB suggests that the Principal Investigator consider the following:

- Explicitly mention that the study is "research" and not a "job." (Sample statement to include in the consent information: "This is an academic not-for-profit research study. This form is

designed to give you information about this study. We will describe this study to you and answer any of your questions.")

- Address whether or not the compensation is contingent upon certain conditions. Ensure that the complexity of the task and the amount of time expected for completion is reasonable and communicated clearly in the consent process.

3. Additional Special Considerations Involving Use of Social Media in Research

- Consent for enrollment into the study should always be a process that is independent from the recruitment (e.g., before or as part of the survey process). It is generally not acceptable to consent the individual only as part of the recruitment message.
- The Principal Investigator must clarify that the data are collected only when the participant accesses the survey site. In other words, no opportunistic data can be collected. For example: if an investigator sends a link to individuals to access a survey or an application, s/he may not collect information about the person if they click on the link to access the consent/survey or application. If data is collected in this manner, it would qualify as deception research and require debriefing and the ability of the unsuspecting participant to withdraw their data.
- The Principal Investigator may not collect any information from any individual who declines to participate in the study. Exception: if the process for making an accept/decline decision is the subject of the study, the investigator must acknowledge the deception in a subsequent debriefing process and, when possible, allow the individual the opportunity to withdraw her/his response.
- The Principal Investigator must ensure safeguards are in place for screening children, prisoners, and other vulnerable populations, unless these populations are the intended participants of their study.
- The Principal Investigator may seek to get information not only about and from the individual specifically recruited for the study, but also about individuals connected to the recruited participant's social network (e.g., his/her "friends") by accessing the information that those individuals have made available to the recruited participant. In this circumstance the participant population now includes the "friends" who may need to be consented before data about them can be included in the study. Information made available by "friends" on the "wall" or another public place on the recruited participant's social network may be considered to belong to the participant and can be included without the explicit consent of the "friend," if the study itself is considered to be no more than minimal risk. The Principal Investigator must exercise caution to protect the identity of such participants and report results in aggregate as much as possible.
- An opt-out type of consent may be possible. Participant informs friends that data posted on her/his site between certain dates will be available for research. Those not wanting their data included should inform her/him or refrain from posting. This waiver of consent should be acceptable for no more than minimal risk studies.

4. Security of Data and Confidentiality

Collecting data over the internet can increase potential risks to confidentiality because of third party sites, the risk of third-party interception when transmitting data across a network and the impossibility of ensuring that data is completely destroyed once the work is complete. Also, data collected using some internet sites, such as the Amazon Mechanical Turk data collection tool, will reside on the Amazon or other third-party servers and no assurance can be made as to its use for purposes other than the research. The Principal Investigator is advised to therefore collect data using a third-party survey software, such as Qualtrics or REDCap, with known policies for data security and anonymity.

In addition, participants should be informed of these potential risks in the informed consent document. For example:

- "Although every reasonable effort has been taken, confidentiality during actual internet communication procedures cannot be guaranteed."
- "Your confidentiality will be kept to the degree permitted by the technology being used. No guarantees can be made regarding the interception of data sent via the internet by any third parties."
- "Data may exist on backups or server logs beyond the timeframe of this research project."

5. Use of mobile devices and other emerging technology

This type of research may involve the use of existing data and/or interaction with or intervention in the person's environment. In either case, the guidance in the preceding descriptions will apply as appropriate to the research design. However, additional considerations apply to research that involves the collection of data via social media applications that are networked with mobile devices, or by installing applications on a person's mobile device to collect data:

- The Principal Investigator must not collect location information or other data that is not explicitly stated to the study participant in the consent form.
- If the research involves installing a mobile application (app) on a person's smartphone or other device for the purposes of data collection, the researcher must describe how the app will be deactivated at the conclusion of the study. This should be done either by making the deactivation part of the study's exit procedures, or by providing instructions to study participants on how to deactivate the app. Additionally, the Principal Investigator should describe plans to ensure they do not continue to collect data once the study is complete, in case a participant does not effectively deactivate the app.
- If the study involves the use of a mobile device provided by the Principal Investigator, the Principal Investigator should explain the confidentiality safeguards that are in place (e.g., how s/he will ensure the data is under the research team's control and that third parties do not have access to it), as appropriate to the study.

6, Special Considerations Regarding Use of TikTok in Human Subjects Research at PNWU

The Federal Acquisition Regulations, Section FAR 52.204-27, prohibits federal contractors, with limited exceptions, from having or using TikTok or other applications or services developed by ByteDance Limited on any "information technology" owned, managed, used or provided by the federal contractor, including equipment provided by the contractor's employees. Since PNWU is a federal contractor that uses its IT Systems to provide services to the federal government, the PNWU community, including its faculty and staff, should not use the TikTok App or access TikTok services through the internet using:

- PNWU IT Systems;
- PNWU issued electronic equipment, such as desktop and lap top computers or mobile phones, or
- Personally owned devices that are also used to conduct official PNWU business or other academic activities, such as research at PNWU. *See* OSA Procedure # _____ "*Accessing TikTok on PWNU IT Systems or Electronic Devices or Other Devices Used in the Conduct of PNWU Activities*."

Principal Investigators or other members of the PNWU Community who wish to conduct or participate in the conduct of human subjects' research at PNWU may not access or use TikTok to recruit research

participants or conduct any aspect of human subjects research at PNWU, without the prior written permission of OSA. Note well, exceptions to the federal ban on use of TikTok under the FAR are very limited. See OSA TikTok Procedure # ____, cited above.

In addition to prior written approval by OSA, the PNWU IRB must also give prior approval for the use of TikTok in recruiting human subject research candidates or in conducting any aspect of human subjects' research at PNWU. In particular, the OSA approved exception to the federal ban on TikTok must be clearly set forth in the IRB approved written protocol that is required for the human subjects' research at PNWU. The PNWU IRB shall maintain ongoing oversight of compliance with the TikTok provisions of the approved protocol throughout the conduct of the human subjects' research. Approval for any changes or modifications to this protocol must be obtained in advance from the PNWU IRB.

Investigator Procedures:

1. Decide how the internet will be used and/or what social media platform(s) will be used (e.g., LinkedIn, Twitter, Instagram, Snapchat, Facebook, YouTube, Tik Tok, as well as websites and blogs).

2. Review the PNWU Network Acceptable Use Policy and the standard operating procedure for data management, de-identification and storage of identifiable data (SOP 113 Data Management and Disposition).

3. Determine what permissions are required, and if there are restrictions on the use of the internet or social media platform(s). Failure to obtain appropriate permission could have consequences including the loss of collected data, reputational harm to the investigator and the University, and legal action.
    a. Terms of use on social media sites vary and may be revised over time. The Principal Investigator should be aware of any research related restrictions on the use of the social media/networking site through which they intend to conduct their research activities. The Principal Investigator is responsible for securing the necessary permissions as well as complying with required permissions and restrictions. The principal investigator must check the policies and terms of use on a regular basis to ensure compliance. Compliance checks for the terms of use must be completed and documented annually. If the terms of use are revised in a way that is relevant for the protocol's compliance, the principal investigator is responsible for notifying the IRB.
    b. Neither PNWU nor the IRB can take responsibility for ensuring that the terms and conditions for conducting research on such sites have been met. Failure to ascertain and acquire appropriate permissions could result in consequences that may include sequestration or loss of the data collected, reputational harm to the researcher and the institution and in the worst case, legal action by the site manager or participants.

4. Schedule an appointment with the Office of Scholarly Activity to discuss whether or not legal counsel may be required to ensure compliance with terms of use.

5. The IRB application must include:
    a. A detailed explanation of how the internet/social media platform will be used for the study (e.g., recruitment, interaction with potential participants, observation or recording of already existing data, collecting new data via direct interaction with members of a site such as Facebook) and the social media platform(s) that will be used for the study;

b. A complete description of what data will be collected and how the data will be collected;
c. The URL website address/addresses;
d. Information about site terms of use, restrictions, permissions sought, as well as, evidence of permissions received;
e. As much, detail as possible, when used for recruiting purposes. This should include:
    i. information about where the social media posting will be placed, if the posting will be placed in paid site or if the information will be posted in closed, open or moderated groups, as well as if the recruitment will be active or passive;
    ii. the recruitment material must clearly specify the age limit for participation;
    iii. recruitment must comply with applicable federal laws and regulations as well as terms of use of the relevant website(s);
    iv. what education will be provided to the participants regarding study social media activity.
    v. Only IRB approved recruitment materials may be posted. Additional commentary about the study may not be posted.
f. All related study materials that are part of the study (e.g., study face page, recruitment page or information pages);
g. A detailed description of how consent will be obtained and documented (e.g. subject signature), how subject comprehension will be assessed, and in some cases how identification of the subject will be verified. (e.g., identity can be established/verified by showing picture id that includes first and last name. At that point an ID or PIN can be assigned to the subject and comprehension can be assessed by asking the subject questions about the study). This may be especially challenging with studies involving children and in the absence of in-person contact. It is also important to note that age of majority for consent differs from state to state.

IRB Procedures:

1. Review and process submissions following normal procedures described in PNWU SOP 124 Review and Approval of Studies.
2. Review study proposal for compliance with applicable federal regulations, state law, and PNWU policies and procedures.
3. Request a legal consultation when additional expertise is needed to ensure compliance with legal requirements in the terms of use, federal regulations, or state law.
4. Ensure that risks to subjects are minimized.
5. Ensure that study proposal respects ethical norms.
    a. Study is accurately represented in recruitment materials;
    b. Proposed recruitment does not involve contact that could create undue influence or stigmatize the potential participants.
    c. Recruitment does not involve deception.
    d. Ensure that an appropriate communication plan is in place for how the research team will handle online communication from enrolled participants.
    e. Consent appropriate to the study protocol and level of subject contact.

References:

1. Food and Drug Administration (FDA) Federal Regulations (21 CFR 50, 54, 56, 312, 314, 600, 601, 812 and 814) http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfcfr/cfrsearch.cfm

2. Department of Health and Human Services (DHHS) Regulations (45 CFR 46 Subparts A, B, C, and D) http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html
3. International Conference on Harmonization (ICH) Good Clinical Practice (GCP) guidelines https://www.fda.gov/scienceresearch/specialtopics/runningclinicaltrials/guidancesinformationsheetsandnotices/ucm219488.htm
4. The Belmont Report hhs.gov/ohrp/regulations-and-policy/Belmont-report/index.html
5. Attachment B: Considerations and Recommendations concerning Internet Research and Human Subjects Research Regulations, Secretary's Advisory Committee On Human Research Protections, March 2013
6. Harvard Catalyst: 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 accessed 10/21/2020.
7. Recruiting Study Subjects: Guidance for Institutional Review Boards and Clinical Investigators. US Food and Drug Administration. https://www.fda.gov/regulatory-information/search-fda-guidance-documents/recruiting-study-subjects accessed 11/5/2020
8. PNWU Standard Operating Procedure 113: Data Management and Disposition
9. PNWU Network Acceptable Use Policy
10. FAR 52.204-27, Prohibition of ByteDance Covered Application (Tik Tok).

Revision History:

Version/ Effective Date	Author	Section Changed & Reason for Revision
.00 / 9-14-2023	C. Case/B. Roach	Original SOP

Appendices: