

Technology & new media

A. Purpose

To provide a summary of investigator responsibilities when using online sites as part of a research activity.

B. Revision history

Originally issued: November 2013

C. Persons affected

All NWHSU University faculty, staff, students, patients, and agents of the institution

D. Policy

Online research sources such as Facebook, Twitter, blogs, chat rooms, discussion forums, and other social networking sites will be treated as publicly available data by the IRB in a very broad sense, and with a number of limitations.

Privacy Statements & Terms of Use

It is the responsibility of the researcher to check the privacy statement and terms of use of any site being used for research purposes. For example, Facebook's privacy policy currently states that consent must be obtained for the use of any data from a Facebook user's page. The campus expects researchers to adhere to the written policies of any site used for research. The IRB expects that researchers will either: 1) Obtain consent to use data from an individual's Facebook page or 2) Make an appropriate argument as part of the application process as to why the IRB should waive consent for the purposes of the project.

Publicly Available

The IRB does not consider sites that require a login and password to be publicly available data; therefore, participants must be consented before an investigator can observe or interact with participants. Members of sites that require a login have an expectation of privacy and do not expect that anything they post will be used for research purposes. In some circumstances, researchers can petition the IRB for a waiver of consent. In these situations, researchers will need to provide convincing evidence for why a waiver of consent is appropriate/ necessary.

Sensitive Topics

Protocols which involve sensitive topics such as the discussion of illegal behaviors, health related issues, and/or will likely involve participation by minors, will be reviewed on a case-by-case basis. If a study from this category is approved, it is likely that the IRB will require that researchers paraphrase any quotes, so they cannot be traced directly back to the participant.

Not Human Subjects Research

Some technology based studies may not meet the definition of human subjects research per the federal regulations, and therefore, do not require IRB review. An example would be if a researcher is studying how many Facebook pages include images of families; the unit of measure in this case is the page, and not a human subject. If no personally-identifiable data is being collected, this is not human subjects research and does not require IRB review.

Identifiable Information

Research using public documents such as newspapers, books, or journals that are published online that involve no other data source(s) is not considered human subjects research, even if identifiable persons authored or are included



in the public documents; however, any research that combines identifiable information about individuals obtained from public documents, when combined with identifiable information obtained from other sources, may be considered human subjects research and thus subject to IRB review for further consideration regarding its status.

Data Mining

Facebook, Twitter, and others may provide data mining services where their developers will mine data from the site, for a fee, at the researcher's request. Depending on the scope of the data mining, the IRB may treat the data differently because the data collection activity would be done by the site and (likely) provided to the researcher without direct identifiers. The IRB deals with this type of research activity on a case-by-case basis. Depending on the on the likelihood of identifiable data being a part of the dataset, the IRB may treat it as secondary data analysis, not human subjects research, or waive consent for the use of the data for research purposes.