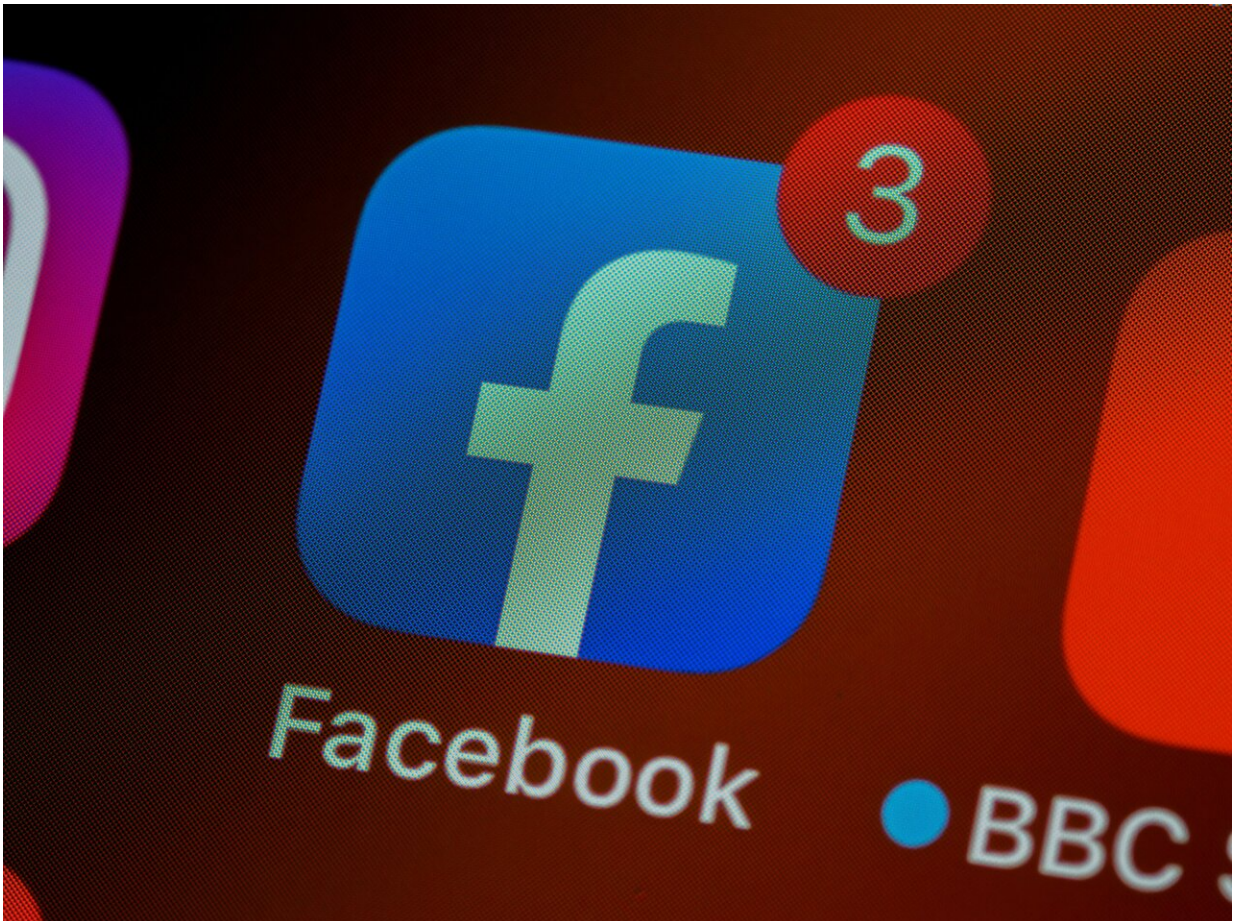


A call for ethical guidelines for social media data use in public health research

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Three studies by CUNY SPH investigators highlight the need for

stronger guidance on research ethics for using data from social media platforms in public health research, especially the use of personal identifiers.

For a [study](#) published in *Social Science & Medicine*, alumni Hannah Stuart Lathan, Joshua P. Tanner and Rachel Wormer, with doctoral graduate and researcher Amy Kwan, Research Assistant Courtney Takats, Professor Diana Romero and Associate Professor Heidi Jones conducted a systematic review of Facebook-based public health research published in peer-reviewed journals.

Researchers increasingly use Facebook content and activity as a [data source](#) since much of it is publicly available, but the authors question the ethics of this, given that users generally do not read or understand the platform's privacy policies and are unaware of the visibility of their data to anyone aside from their Facebook "friends." Moreover, when made aware of Facebook's privacy policies, users are overwhelmingly unsupportive.

Almost two thirds of the studies reviewed included users' written content, mostly verbatim user posts. Among those studies whose content had not been removed the platform, the research team was able to locate users or posts in 10 minutes or less for half of them. A significant amount of personal information was attached to this content, including race, age, education level and relationship status.

"It was concerning to identify these users with such minimal effort, especially those who may be considered part of a vulnerable population, such as adolescents and people experiencing [mental health problems](#) or [substance use disorders](#)," says Lathan, who led this review for her master's essay.

A [study](#) by the same team with alumna Dari Goldman in the *Journal of*

Medical Internet Research reviewed articles using data from X, the platform previously known as Twitter, and found that only a third (32%) sought ethical approval from an institutional review board, while 17% included identifying information on X users or tweets and 36% attempted to anonymize identifiers.

Finally, a [third study](#) in the same journal, led by alum Joshua Tanner for his master's essay, sought to understand the types of [public health research](#) being implemented with YouTube data and the methodologies and research ethics processes applied to this research.

The majority (69%) of articles made no mention of ethical considerations in [study design](#) or data collection. Thirty-three (28%) contained identifying information about content creators or video commenter. About a quarter of studies sought Institutional Review Board approval (26%), but only one sought informed consent from content creators.

"The lack of clarity around inclusion of YouTube videos in research is especially problematic, given that it is not always clear whether all individuals included in a video have consented to being taped and having the video shared publicly," says Tanner.

The authors assert that public health researchers should not be left to figure out the very complex and oftentimes opaque terrain of privacy aspects of social media data, much less make individual decisions on what data should or should not be protected.

Many studies included in these three interrelated systematic reviews found authors making their own decisions, such as anonymizing or not including content for social media users perceived to be children, highlighting researchers' discomfort with the lack of ethical oversight. They recommend that committees overseeing research with [human](#)

[subjects](#) develop guidelines for best ethical practices for research involving data from social media platforms.

"These findings underscore the need in the research community for better protection of user data across [social media platforms](#), with clearer guidance around anonymization and informed consent," says Dr. Jones. "It would be startling to read one of your Facebook posts or YouTube or X comments verbatim in a peer-reviewed journal article—this is not something most users consider as a possibility."

More information: Hannah Stuart Lathan et al, Ethical considerations and methodological uses of Facebook data in public health research: A systematic review, *Social Science & Medicine* (2023). [DOI: 10.1016/j.socscimed.2023.115807](#)

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