

Ethical Considerations for Social Media Research

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Disclosure

I have no relevant personal/professional/financial relationship(s) with respect to this educational activity

Types of Social Media Health Research



Please type into the chat ways that you have used social media for health research.

If you have not done any social media-based research yet, type in ways you think social media could be used for health research.

Types of Social Media Health Research

Collecting/Analyzing
Social Media Data

Social Media as the
Medium for
Intervention

Recruitment via
Social Media

Examples of Social Media Data-Based Health Research

The impact of social networks/social media exposures on health behaviors

How social media users gather and exchange health-related information and share personal experiences

The spread of public health-related information/misinformation

The prevalence of health-related behaviors posted on social media

Development of algorithms to predict health outcomes or outbreaks

Overview of Ethical Considerations



User involvement in privacy settings



Website purpose and privacy statements



Legal right to privacy



Confidentiality



Likely type of review

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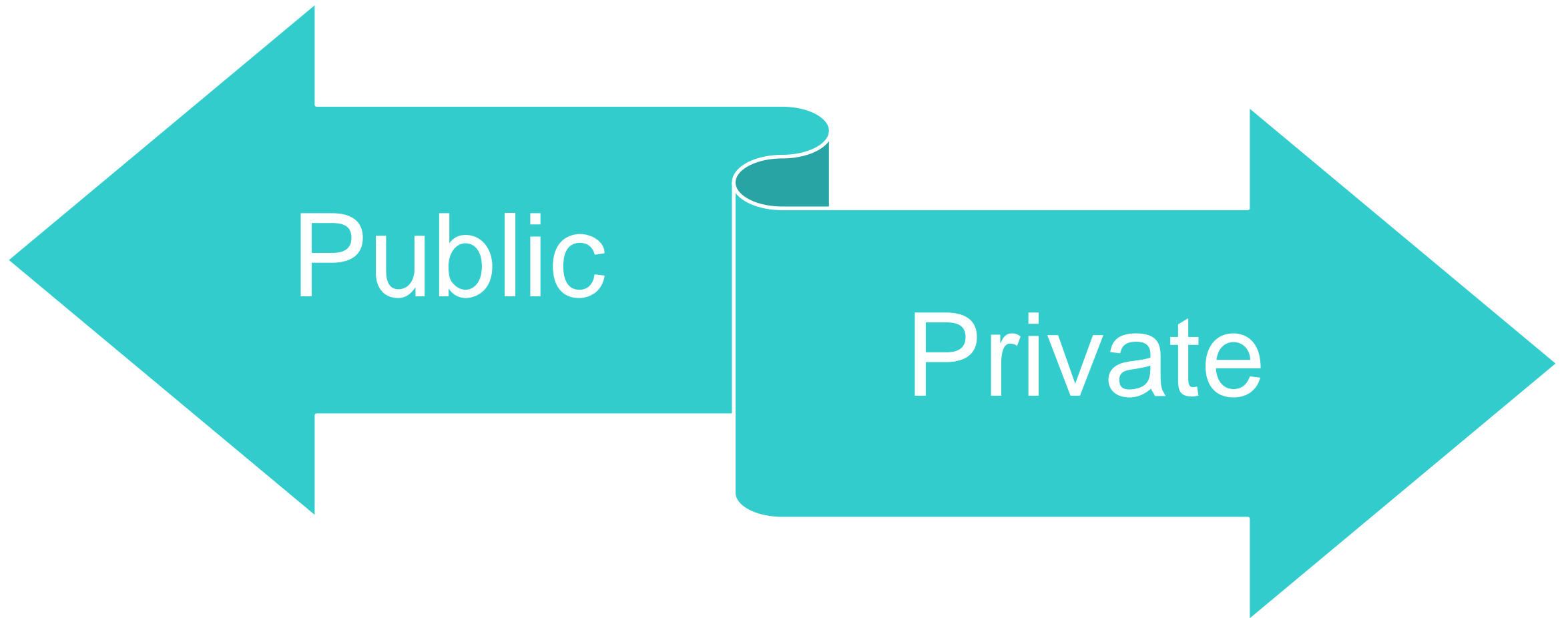


Confidentiality



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Purpose: “Facebook was built to bring people closer together. We help you connect with friends and family, discover local events and find groups to join.”

Privacy:

- Users have control over the privacy of their profile and every post
 - “When something is **Public**, that means anyone can see it, even people you aren’t friends with, on or off Facebook.”

Website purpose and privacy settings



Information sharing with researchers and academics:

“We also provide information and content to research partners and academics to conduct research that advances scholarship and innovation that support our business or mission, and enhances discovery and innovation on topics of general social welfare, technological advancement, public interest, health and well-being.”

Website purpose and privacy settings



Information sharing with

“ This statement is linked to their internal academic program, which states that they “offer a number of ways for academics to engage with researchers at Facebook.”

, health and

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Likely IRB designation

Legal consideration: Right to Privacy



Courts have concluded that a person has no reasonable expectation of privacy in posts on a social networking website that are made available to the public

Legal consideration: Right to Privacy

Pending Federal Laws

- The CONSENT Act (S. 2639)
- Social Media Privacy and Consumer Rights Act (SB 189)

State Laws

- Passed: California, Maine, and Nevada
- Pending: Minnesota, New York, Washington

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Data can be collected without direct identifiers (e.g., address, phone number, name)



Data can easily be triangulated with indirect identifiers (e.g., quotes, location, health characteristics) to make it identifiable

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Confidentiality



Likely type of review

Couple of Key Definitions

- **Research:** a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.
- **Not Human Subjects Research (NHSR):** does not meet the definition of research OR does not involve human subjects.

Couple of Key Definitions

- **Human subject:** any *living* individual about whom an investigator conducting research obtains
 - information through intervention or interaction with the individual, and uses, studies or analyzes the informationOR
 - obtains, uses, studies, analyzes, or generates identifiable private information
- **Private Information:** includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information that has been provided for specific purposes by an individual and that the individual can reasonably expect will not be made public (for example, a medical record).

Likely type of review by study characteristics

<u>Study Characteristics</u>	May be considered NHSR	May meet criteria for exemption 4	Expedited or Full review likely needed
Website Access			
Researcher interaction with the person who posted			
Subjects can be identified			
Disclosure of data could place subjects at risk			

Likely type of review by study characteristics

<u>Study Characteristics</u>	May be considered NHSR*	May meet criteria for exemption 4	Expedited or Full review likely needed
Website Access	Public (i.e., no log-in)		
Researcher interaction with the person who posted	None		
Subjects can be identified	Information is not identifiable or is identifiable, but public		
Disclosure of data could place subjects at risk	No		

* All four characteristics need to be met

Likely type of review by study characteristics

<u>Study Characteristics</u>	May be considered NHSR*	May meet criteria for exemption 4*	Expedited or Full review likely needed
Website Access	Public (i.e., no login)		
Researcher with the per posted			
Subjects can identified	Not public		
Disclosure of data could place subjects at risk	No		

Note: Effective October 1, 2020, any study that will involve the use of publicly-available information must be submitted to the BUMC IRB.

* All four characteristics need to be met

Likely type of review by study characteristics

<u>Study Characteristics</u>	May be considered NHSR*	May meet criteria for exemption 4*	Expedited or Full review likely needed
Website Access		Log-in required, but users can choose to make information public	
Researcher interaction with the person who posted		None	
Subjects can be identified		Information is not identifiable or is identifiable, but public	
Disclosure of data could place the subject at risk		No	

* All four characteristics need to be met

Likely type of review by study characteristics

<u>Study Characteristics</u>	May be considered NHR	May meet criteria for exemption 4	Expedited or Full review likely needed*
Website Access			Log-in required
Researcher interaction with the person who posted			Yes
Subjects can be identified			Information is identifiable and private
Disclosure of data could place subjects at risk			Yes

* If any of the four characteristics are met, expedited or full board review likely needed

Take Away



Resources

- UConn Center for mHealth and Social Media
 - <https://mhealth.inchip.uconn.edu/>
- Society of Behavioral Medicine BIT SIG
 - <https://www.sbm.org/membership/special-interest-groups>

Questions?

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