The ethics of using social media for HIV/AIDS prevention/research

Stephen R. Latham, JD, PhD
CIRA, Yale University
Chair, Yale Human Subjects Committee
Using Social Media in HIV Research/Intervention

• Non-interactive observation of posted data
• Non-interactive observation of location
• Slightly interactive observation of semi-private data (“friending” on Facebook, “following” otherwise closed tweets on Twitter)
• Subject recruitment, via media or using location, for one-time survey/interview/intervention
• Use of media for periodic reporting of results or other frequent contact
Non-Interactive Uses

• Young et al., Preventive Medicine 63 (2014), 112-115, “Methods of using real-time social media technologies for detection and remote monitoring of HIV outcomes.”

• Analyzed geolocated tweets to create a map of densities of HIV-related tweets; results correlated with county-level HIV case data

• Suggests future uses of Twitter to contact at-risk populations
Non-Interactive Uses


• Created sampling points within Atlanta, and gathered age, race and distance-from-point data for users of sexual network app

• Mapped density areas for app users by race, for use in obtaining representative samples in future studies/interventions
Interactive Uses

• Winetrobe et al., AIDS Care 2014, 26(10), 1303-08, “Associations of unprotected anal intercourse with Grindr-met partners among Grindr-using young men who sex with men in Los Angeles.”

• Used Grindr account to send surveys about sexual habits of Grindr users

• Also gathered demographic data and data about characteristics of profiles (e.g., facial photo? Photo of naked chest/abs? etc.)
Interactive Uses

- 70% of anonymously-surveyed YMSM using Grindr expressed willingness to participate in a smartphone app-based HIV prevention program. Shows promise for utility of app-development in this area.
Regulatory Concerns

• Does your use of social media data involve human subjects?

• Is it “research”?

• If not, no need for IRB approval, or even for IRB determination of exemption
No “Human Subject”

- Merely looking at publicly-available social media data (e.g., Youtube videos, public Facebook postings visible to non-“friends”) is not human subjects research.

- A human subject, by regulation, is one from whom investigator obtains data by interaction or obtains identifiable private information. Examples above are identifiable but arguably not private.

- Stated privacy policies of various social media can back up the idea that post data aren’t private.

- No IRB approval required; but be careful.
Not “Research”

• Regs define research as designed to contribute to generalizable knowledge, so these aren’t research:
  – Creation of a case-study (not generalizable)
  – Use of social media by a physician or public-health worker as device to facilitate clinical follow-up; for treatment rather than for publication
• In general: it’s not research (designed to contribute to generalizable knowledge) unless a major goal of the activity is to learn something for the benefit of people other than the particular subjects.
Human Subjects Research

• If you interact with subject, via “friending” or asking questions; or

• If you gather private information; and

• If you intend to use the information in part to advance general knowledge (i.e., to benefit someone other than your particular subjects)
Exempt from IRB Review

• Determination of exemption must be made by IRB staff

• Observation, interview or survey, unless:
  – Subject can be identified directly or indirectly; AND
  – Disclosure of data could put subject at risk for criminal or civil liability, or damage to financial standing, reputation or employability.
Exempt from Review, cont.

• So a study is exempt if you don’t gather information that would permit direct or indirect identification of subjects; or if the information gathered has no consequences for stigma, reputation, liability.
“Expedited Review”

- Survey, interview, focus group research; research on group characteristics or behavior; if and only if
- Below minimal risk
- “Minimal risk” is below that faced in ordinary life or in a regular doctor visit
- Danger of stigma or dangers to relationships place a study above minimal risk level
Minimal risk in social media: crucial questions

• If subjects can’t be identified, risk to them is minimal. But:

• How much data makes someone “identifiable?”
  – Harvard Facebook social network study
  – Data enough to “triangulate” onto subjects?

• Risk of stigma/liability to subjects
  – Widely variable according to country where research is conducted
  – In some countries, mere identification as a research subject would impose grave risks
Using Social Media to Contact Subjects

• Baseline ethical concerns:
  – Subjects didn’t sign onto the social media in order to become research subjects; they may view technically public information as “private.” So mere approach is potentially invasive/offensive.
Using Social Media to Contact Subjects, cont.

• Make it clear you’re a researcher
• Make it clear they don’t have to agree to participate, and that they can withdraw at any time
• Use adequate informed consent
• Remember the social character of social media: one person’s consent may expose data belonging to their “friends.” Take care to shield identity of index subject if you’re snowball sampling (e.g., using “friends of friends” or “followers of followers.”)
General Concerns in Social Media Research

- Informed consent: quality of online consent is hard to gauge
- Careful protection of identifying information, if gathered: encryption, coding, password protection, etc.
- Provide contact information for questions
- Put plan in place for action if your research might reveal actionable information (suicidality, mandatorily reportable behavior)
General Concerns, cont.

- Separate researcher presence on web from personal presence: don’t use personal Facebook or Twitter or Grindr account as base for research
- Waiver of signed written consent in cases where consent would be a source of identifying information
Concerns in publication of Social Media research

• Take care to avoid possible re-identification
• Don’t publish screen-shots or direct text quotations, which are searchable
Sources:

• General: Moreno et al., Cyberpsychology, Behavior and Social Networking 2013, 16(9), 708-13, “Ethics of social media research, common concerns and practical considerations.”

• Harvard study: Zimmermer, Ethics Inf. Technol (2010), 12:313-25, “But the data is already public”: on the ethics of research in Facebook