

## 10 'Thorny' Data Collection Scenarios

- 1) A research study is examining an online eating disorder forum to identify its intersections with depression. Within the study, direct quotations from the online forum posts are included which have the potential of being traced back to the original poster as the quotation can be inputted into a Google search. Despite this, the authors state that they have respected user anonymity by omitting usernames and other identifying information (i.e. age, sex, location) from the direct quotations. Was this an ethically sound approach?
- 2) In a research study exploring the use of online forums by infertile women, the researchers discuss how they were exempt from obtaining participant consent due to the public nature of discussion in the online forum. The researchers highlight that none of the users should have had a reasonable expectation of privacy as they were voluntarily participating in a public domain. Is this justification adequate enough to mine data without the consent of the original poster?
- 3) In a Reddit thread for sexual assault survivors, a researcher obtained quotations non-verbatim for a research study examining the use of Reddit for discussions of sexual violence. The researcher admits that their presence was not detrimental to the sensitive environment of the online forum as they opted for a 'passive' approach of not participating in or making themselves known to the online forum. Further, the use of non-verbatim quotes protects user privacy as the quotes cannot be traced back. In environments where sensitive topics are discussed with the primary objective of obtaining support or advice, is it more beneficial for users to know of a researcher's presence where their personal traumas are discussed or not?
- 4) In a study examining the use of Twitter for discussions of waterpipe smoking methods, ethical approval was not obtained due to the public accessibility of the Tweets and the omission of usernames to protect privacy. Since Twitter discloses to its users that third-parties may obtain their data in the "Terms and Conditions" of the site, were the researchers justified in not receiving ethical approval or participant consent?
- 5) In a study exploring the use of Reddit for support during substance abuse recovery, a researcher expressed how they did not obtain consent from posters as it would be too difficult considering the group size of over 10,000 members and due to the public accessibility of the group. Is the nature of the Reddit thread being observed justifiable enough to waive obtaining informed consent?
- 6) An analysis of a suicide prevention forum is conducted by researchers to explore its use by young people. When discussing the ethical considerations of the study, the researchers express how they obtained consent to use the forum posts not by the participants but the moderators instead. Was the consent received from the forum moderators adequate enough to diminish the need for participant consent?
- 7) While investigating the behaviour of Internet trolls within an online forum, a researcher states that the data from the forum could be obtained without consent from its participants as their behaviour was freely observable. Further, those behaviours exhibited within the public space were not elicited nor encouraged by the researcher himself. Does this explanation warrant the use of other people's data without their permission?

- 8) In a study exploring the use of online discussion forums by stroke survivors and their families, the researchers state that they mined data from the forum freely due to the public nature of the discussion. Despite not making their presence known to participants, the researchers state that those researchers who did make their presence known within the forum gained positive reception from forum commenters. As such, the researchers justify not obtaining consent since nonetheless, a majority of users would have reacted positively to having their data used for research purposes.
- 9) A study investigates the use of social media by horse riders through both a public forum and private Facebook group. Though the confidentiality of all users were maintained regardless of the group, consent to use user responses was obtained for the private group but deemed unnecessary for the public forum. Is the different treatment of consent for private versus public discussions warranted?
- 10) In a particular study exploring the future of sexual intimacy with robots, the researchers acknowledge the sensitive nature of the public discussion as well as the notion that users may not anticipate that their responses be used for scholarly research. To ensure the least amount of disturbance to participants by virtue of their research, the researchers adopt a “moderate disguise” approach. By doing so, they reveal the forum name while altering quotations so they cannot be traced back to the original poster. Is this “moderate disguise” adequate enough in an environment where a highly personal topic such as that of sexual intimacy is discussed?