



Re-evaluating standards of human subjects protection for sensitive health data in social media networks

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ABSTRACT

This study addresses ethical questions about conducting health science research using network data from social media platforms. We provide examples of ethically problematic areas related to participant consent, expectation of privacy, and social media networks. Further, to illustrate how researchers can maintain ethical integrity while leveraging social media networks, we describe a study that demonstrates the ability to use social media to identify individuals affected by cancer. We discuss best practices and ethical guidelines for studying social media network data, including data collection, analysis, and reporting.

Introduction

Social media platforms have saturated our media landscape and permeated our social interactions, and use of social media services continues to grow rapidly (Pew Research Center, 2018). These platforms have provided researchers with rich datasets that support innovative health investigations across multiple disciplines. For example, using data from social media, health researchers have been able to track factors surrounding suicide attempts (Won et al., 2013), monitor disease outbreaks (Chew and Eysenbach, 2010; Collier et al., 2011), and investigate sentiment toward tobacco products (Myslin et al., 2013).

Social network analysis (SNA) can help researchers understand the importance of relationships between actors in a network, with theories and measures that explain how relationships can affect individuals, groups, and entire networks (Wasserman and Faust, 1994). Prior to the development of social media platforms, SNA typically relied on offline data collection through paper surveys. However, the emergence of social media sites has provided copious relationship data that are ideal for SNA. Platforms such as Twitter and Facebook rely on user relationships and interactions to generate valuable data.

Using social media data has introduced ethical challenges for health researchers. Ethical standards and norms developed over the past several decades have led to specific requirements and processes for obtaining informed consent and managing private data. However,

guidelines for the use of social media in health research remain largely incomplete and often contradictory (Adair-Hatch, 2015; Andrews, 2012; Gelinis et al., 2017). At a minimum, approval by institutional review boards (IRB) is necessary to demonstrate regulatory adherence; however, clear and widely accepted standards for social media research have not been established. There are differing opinions on how traditional guidelines—such as expectation of privacy—can be mapped onto social media platforms. Additionally, health researchers do not always understand the legal and privacy implications of examining potentially private health information on social media. For example, in the US, some states are starting to enact legislation that protects the online privacy of individuals (Pourmand et al., 2018). However, the language in some of these legislative efforts contradict that of the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, which was enacted to protect personally identifiable health information from misuse (US Department of Health and Human Services, 2019). For example, if a researcher were to identify a suicidal individual, for which HIPAA would allow sharing of private health information to secure intervention, state legislation may require consent from the individual on social media before sharing such information (Pourmand et al., 2018). Currently, it is at the discretion of the researcher to determine the appropriate course of action.

While preliminary recommendations have been suggested for setting ethical standards for social media research (Pagoto and Nebeker, 2019),

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questions remain around standards for guiding researchers conducting SNA studies using social media data. For example, how are observational studies affected by processes of informed consent? What type of data can be considered acceptable? What type of training should be required for researchers studying social media data for health? When should HIPAA regulations be applied? [Townsend and Wallace \(2016\)](#) published a framework for ethical research with social media, which culminated from a workshop held with social media researchers. This framework guides researchers—through a series of questions and case studies—toward appropriate ethical considerations for their individual work. However, it does not put forth specific recommendations focused on certain nuances, e.g., the use of network data. Network data from social media platforms are becoming more prevalent in health science research. Generally, this progress has been a beneficial development in health science fields, as researchers have been able to leverage social network measures and theories (e.g., diffusion of innovation, peer-influence, centrality metrics, etc.) to study disease spread, adolescent substance use, mental health, and many other topics. However, as new and innovative research continues to blur the boundaries between medical ethics and social media network data, recommendations and guidelines are needed to obtain, evaluate, and share such data. As relational data from social media are mined, studies are now responsible for potential health data from alters (i.e., people connected to the primary ego in a network) that are not part of the intended cohort of individuals. How should researchers manage these networked individuals?

Therefore, the purpose of this study was to address issues around conducting health science research using network data from social media platforms. We provide several examples to elucidate ethically problematic areas that could arise at the intersection of participant consent, expectation of privacy, and social media networks. Further, we describe an ongoing project that can serve as a case study to illustrate how researchers can maintain ethical integrity while leveraging social media. For example, we will show how social media network data can be used to derive potentially personal health information without input or consent from users and include a discussion on guidelines for best practices.

Examples from current SOCIAL MEDIA Research

One consideration for conducting health science research using data from social media platforms centers on *if and how researchers are trained to address human subjects and ethical considerations*. For example, some researchers use crowd-sourced coders to analyze tweets collected from the Twitter social media platform ([Cavazos-Rehg et al., 2015](#); [Colombo et al., 2016](#)). While this may be a cost-effective and time-efficient method for analyzing large data sets, it raises concerns around human subjects protections. Federal guidelines mandate that all research personnel involved in the design and conduct of federally-funded human subjects research complete human subjects protections training ([National Institutes of Health, n.d., 2019](#)). However, it is doubtful that crowdsourced coders—who are active participants in the conduct of the research—have this type of training. Even if the tweets to be coded do not contain the individual Twitter handles or other identifying information, the text can easily be pasted into Twitter—or search engines such as Google—and used to identify the Twitter user. This method may also be used to discover other users in their social networks. IRBs—as well as the US Department of Health and Human Services—generally consider use of Twitter data to be of “exempt” status because the data are considered publicly available. This is supported by Twitter’s own terms and conditions ([Twitter, 2019](#)), which explicitly state the public nature of most of the content that is posted, user profiles, and other metadata (e.g., date or time of tweets); they are unique in their decision to maintain public access to data, unlike other social media platforms (e.g., Facebook, Instagram) who have chosen to limit access to user data. Twitter notes that it has specific tools to “make that information

available to websites, apps, and others for their use,” which aligns with the policies of most IRBs. However, these practices are rooted in offline procedures that were developed before the popularity of social media. Additionally, without regulated national standards, each local IRB can have nuances on how to manage online data. These complications can impose structural limitations in how IRBs review new data or social practices. However, privacy of the human subjects being researched still must be maintained ([Cavazos-Rehg et al., 2014](#); [US Department of Health and Human Services, 2009](#)).

Another potential issue is the reporting of network data. In manuscripts that describe research conducted with more traditional data sources, authors are prompted to give information about subjects and their data in great detail. For example, in qualitative studies, direct quotations to represent interesting findings are encouraged ([Anderson, 2010](#)). However, in traditional qualitative research, such as interviews or focus groups that are subject to human subjects protections, there is little risk of the source of the quote being identifiable. In contrast, Twitter is accessible by anyone with an Internet connection; a Twitter account is not necessary to view publicly available tweets. Therefore, researchers studying social media network data must be cognizant of the degree to which their “participants” may be discoverable. For example, in one study examining how health-related messages travel through social networks on Twitter ([Beguerisse-Díaz et al., 2017](#)), a direct quotation with potentially embarrassing content was easily searchable on Twitter, leading directly to the source. Thus, researchers working with social media-derived data should consider only presenting direct quotes that cannot be identified.

Following another tradition of reporting in health research, authors are expected to describe their methodology in great detail, including providing specific range of dates for data collection, subjects’ socio-demographic characteristics, and subjects’ geographic locations. This may be problematic for network data on Twitter, however, because this level of detail can be used to identify specific users. In a social network analysis of cancer communication ([Himelboim and Han, 2014](#)), the authors provided specific details about exact dates of data collection as well as specific search terms. In this case, a reader could use this information to replicate the search on Twitter, potentially identifying subjects. This is not the case for traditional research in which subjects are less likely to be identified by individuals reading a study.

The current study

We introduce a study that is one component of a larger cancer communication project. This component examines Twitter data that is focused on the Stand Up to Cancer organization. We collected information being posted by accounts that follow the organization to qualitatively assess the types of conversations that were taking place on Twitter about cancer. We were also interested in the makeup of this cancer community, i.e., what types of people or organizations collectively are involved in the community and how they are interconnected. This study methodology can help to illustrate the complexities when collecting and reporting on potentially sensitive network data and also demonstrate possible strategies on how to proceed within ethical boundaries.

METHODS: data collection procedures

Data were obtained directly from the Twitter Application Programming Interface (API) in September 2018. Specifically, we developed a Python script capable of generating a list of Twitter IDs corresponding to followers and friends for a particular account. For a given account “Bob,” followers are defined as other Twitter accounts that follow Bob, whereas friends are accounts that Bob follows. These data output included only Twitter IDs (i.e., numeric strings). This allowed for the generation of directed network edges defining follower/friend relationships. A second data collection script was used to collect profile

metadata (e.g., link to account profile, account creation date, aggregate numbers of followers, friends, and tweets) among publicly available accounts for which we had obtained Twitter IDs. All data were collected and stored in accordance with established study procedures as approved by the IRB at the authors' university.

Primary (1st degree) network composition

We first obtained edge data corresponding to all available friends and followers of the @SU2C (Stand Up to Cancer organization) Twitter account. This particular account was chosen as the central node because it had a relatively large number of followers (more than 306,000 at the time of data collection) and an active cancer awareness campaign, including a telethon with extensive celebrity involvement (Entertainment Industry Foundation, n.d. 2019). We chose not to anonymize the @SU2C account for this study because it is a publically known organization and its main website includes links and references to its Twitter presence. We then collected metadata for all friends of @SU2C. At the time of data collection, this included 626 accounts. Trained human coders then classified each of those accounts as cancer-related or cancer-unrelated based on independent coders' review of Twitter user profiles. These reviews consisted of evaluating the user name (e.g., American Cancer Society), profile description (e.g., "cancer survivor," "cancer researcher") as well as the most recent page of tweets from that user (approximately 10–20 tweets). If no indications of cancer-related content were identified in the above information, the account was considered cancer-unrelated. Coders met to adjudicate disagreements and came to consensus on all profiles. Many of the cancer-unrelated accounts were public figures or media networks affiliated with the SU2C telethon. Cancer-related accounts were further sub-classified as either organizational/professional or personal. Human classification positively identified 166 cancer-related accounts in the SU2C 1st degree friend network. Of these, 118 were institutional accounts (e.g., non-government philanthropic foundations, government and academic research institutions), 25 were professionals (e.g., individual oncologists or researchers), and 23 were personal accounts (19 patients and 4 caregivers).

Secondary (cancer-related) network composition

Following the previously described procedures for collecting network edge data, we generated a 2nd degree network of all followers of cancer-related accounts previously identified via the annotated 1st degree network. This resulted in an additional 6,081,873 unique Twitter users.

Results

In the dataset of 2nd degree network followers, the typical user followed only one of the identified cancer-related accounts (See Figure 1), and the maximum number of accounts followed was 109 (by the National Foundation for Cancer Research). For feasibility of profile data collection, we selected a random subsample of up to 100 users at each of these levels (i.e., 100 users who follow 1 cancer-related account, 100 users who follow 2 accounts, etc.), which resulted in 5016 user profiles. Of these accounts, 274 were marked as private and an additional 691 left their profile description blank (89 were both private and blank), providing limited information for further investigation and likely indicating some expectation of individual privacy; therefore, we chose to ignore these accounts for any analysis. Among the profiles for which profile descriptions were available, 1954 contained the word "cancer" (43 private accounts), and 209 contained the phrase "cancer survivor" (10 private accounts). Based on qualitative review of 10 individuals mentioning "cancer survivor," 9 were confirmed as having a personal cancer diagnosis and provided individual information such as number of times cancer occurred and types of cancer (e.g., breast, lung, bone,

ovarian). This information might be considered particularly sensitive; we collected no additional data (e.g., tweets, pictures) from any of the accounts. The decisions for anonymity are clear examples of how we—as researchers—consciously chose to explicitly reveal the @SU2C account while anonymizing everyone in their network, i.e., their followers, and followers of followers. While @SU2C is a public entity with links to their Twitter account from other public websites, their followers cannot be considered as such, and revealing their information did not have a benefit to the scope of this study that outweighed the potential loss of privacy in personal health information.

Discussion

Overall, this pilot study was successful in identifying individuals personally affected by cancer through the use of network data on the Twitter platform. These data were publicly available at the time of collection and analyses. However, it is highly unlikely that observed Twitter users intended for their network connections to be used in this particular manner (Fiesler and Proferes, 2018). Specifically, the choice to follow cancer-related accounts may seem fairly innocuous for a typical Twitter user. However, broader analysis of such network characteristics has potential to identify users' latent health conditions. This is particularly concerning as there may have been users who were identified as high-risk through the network model and who may have been directly affected by cancer, but who chose to not overtly share such personal health information. This leads to downstream concerns about the "outing" of affected or at-risk populations, which adds additional ethical implications due to the possible identification of familial risk factors. The impact of this information has a broad range, e.g., allowing companies to target users for advertisements, raising health care costs or insurance rates, or potentially losing employment. This pilot study demonstrated an example of how health data can be inadvertently collected as part of an academic network research project with arguably wholesome goals; however, a data mining, pharmaceutical, or insurance company could leverage the same methods for less benign purposes. There are many examples where the advancements of science risk being appropriated for malevolent uses, e.g., biology and virology for bioterrorism or nuclear physics for atomic bombs, although we do not claim social media health data as equal in scope or severity. However, we can learn important lessons from such examples, including the need for the scientific community to understand these implications and stand together against such uses, for tools to be created to that can support vigilance and monitoring for such activities, and to realize there are potential uses that have not been considered. While our study showed the ability to identify potential individuals affected by cancer, other social media research has focused on even more sensitive health data, including sexually transmitted infection status or illicit substance use (Gabarron et al., 2014; Katsuki et al., 2015). The ethical implications in such cases are particularly troublesome, as researchers could use a similar method of identifying individuals based on network data.

Prior to the deluge of social media data becoming readily available, network researchers using "paper and pencil" methods were less likely to be confronted with ethical concerns that we have discussed. In traditional network studies, participants might be asked who their friends are, who they might go to for advice, or other questions about their personal social network. In these cases, very little is known about the alters, other than some relationship with the participant; in contrast with our study example, we are able to not only retrieve an individual's Twitter network without consent, but we can also derive personal information about these individuals. It is worth noting that this process is more limited on other social media platforms, e.g., Instagram, where the tools limit the type of data mining that is permissible. Privacy issues with network data have effects beyond the scope of research results. For example, traditional (non-social media) use of snowball sampling to recruit participants considers an initial cohort of "seed" participants, and then utilizes their social network in order to recruit additional

participants (Biernacki and Waldorf, 1981). In such cases, these alters are afforded the full process of informed consent. In contrast, when similar processes are mapped to the social media realm, the nature of each social media platform provides more personal information on new participants—without any user consent. As our study demonstrated, there is private health information that researchers can derive from any person's online social network. By including subjects in our primary study through multiple levels of ties from an initial seed account, we are inherently applying snowball sampling. However, snowball sampling has the implicit requirement that the seed participants are acting as “blind” recruiters; no information is known about potential friends being recruited unless they proactively engage with an actual study team member. On social media, the analogous process could be targeted to specific alters in a person's network because researchers have access to personal information—prior to consent—that could identify them as eligible subjects. In each of these cases, whether gathering study data or recruiting, the availability of personal data from social media networks has changed the expectation of ethical protections afforded to study participants, or even potential participants.

We do not advocate for strict recommendations that would hinder research; rather, we suggest a balance between public health imperatives, research ethics, and individual expectations of privacy. In this manuscript, we describe an example of a study that proceeds at such a balance. Our procedures were developed so that ethics were considered and discussed at every step of the study, including data collection, analysis, and reporting. Importantly, we recommend the minimum criteria be applied when conducting network health research using social media data:

Consent: It is not always feasible nor appropriate to obtain written consent from individuals on social media platforms. For example, individuals using the forum Reddit generally obscure their identities with usernames, and “going real-life” is sometimes discouraged, complicating the ability for researchers to confirm identities. There is general agreement that individual consent is not necessary for researchers to use publicly available data, under the Federal Policy for the Protection of Human Subjects (also known as the “Common Rule”; Federal Register, 2017). Therefore, many researchers will obtain waivers for consent from their IRB when gathering publicly available data from sources such as Reddit, YouTube, and non-private Twitter accounts. However, as researchers have shown how network analysis can lead to re-identification of users and the potential exposure of information not intended to be public (Narayanan and Shmatikov, 2009; Su et al., 2017), it cannot always be assumed that this waiver of consent should be applicable to other individuals within a user's social network. Thus, researchers utilizing network data gathered from ostensibly public sources must consider obligations beyond consent as defined by the Common Rule. As suggested by Carpenter and Dittrich (2012), we recommend moving beyond ethical review from simply an informed consent perspective to “a risk analysis review that addresses potential harms stemming from research in which a researcher does not directly interact with the at-risk individuals” (p. 4). In doing so, researchers who might otherwise feel informed consent is not necessary would be also compelled to address the ethical implications of possible harm to broader populations outside the immediate subjects. Foreseeing broader harms or risks associated with a research project is often difficult, and we point researchers to the Association of Internet Researchers ethical guidelines for a sets of questions to prompt reflection about ethical decision making within the specific context of one's study (Markham and Buchanan, 2012).

Respecting Context: To guide the risk analysis suggested above, we further suggest researchers turn to Nissenbaum (2009) theory of “contextual integrity” to ensure social media research activities respect the context under which users originally shared data online. Contextual integrity is a benchmark theory of privacy, a conceptual framework that links the protection of personal information to the norms of personal information flow within specific contexts. Rejecting the traditional dichotomy of public versus private information, the theory of contextual

integrity ties adequate protection of subjects to respecting informational norms within in specific contexts. As Zimmer (2018) has shown, contextual integrity provides a useful heuristic to help social media researchers engage in the type of risk assessments argued for above by urging consideration of contextual norms of information flow and broader expectations of users who share information in online forums. Rather than simply relying on a consent-based model that might suggest “the data is already public” and thus no harm could occur, contextual integrity can provide a much more nuanced—and contextually sensitive—approach to considering the ethics of a particular action or intervention within a social network setting.

Compliance, Training, and Oversight: Many researchers who are delving into the realm of social media research, including SNA, may not have had formal training in ethics and responsible conduct of research using these methods. Indeed, this is an area that many IRBs are struggling with, and recommendations for researchers in these areas are only slowly emerging. Until human protections agencies are able to “catch up” to the fast-paced evolution of research conducted using social media, the onus to conduct these types of studies is on the individual researcher or lead investigator. In some cases, it may be necessary for an additional level of precaution to be taken. For example, although crowdsourced human coders may be cost-effective for coding large sets of data, the risks of unintended “outing” of social media users by coders not trained in human subjects protections may outweigh the benefits. All researchers that will have access to sensitive data should have up-to-date training in research ethics and specific health-focused topics. HIPAA privacy rules remain in effect even when the data are in the public domain (e.g., US Department of Health and Human Services, 2018), although it does not explicitly cover health data that is patient-generated (Cohen and Mello, 2018). Nonetheless, researchers should strive to remain cognizant of the reporting of patient health information. We further recommend that research teams, including data scientists, coders/annotators, and co-authors have thoughtful discussions about context-specific ethics prior to engaging with project data. The current context of cancer is similar to other health contexts in terms of having a potential impact on insurability or employability. Other sensitive health topics, such as suffering from particular mental health or substance use disorders, carrying an infectious disease, or being a victim of interpersonal violence, certainly warrant additional considerations.

Data Handling and Privacy: user data should always be de-identified as soon as possible in the data collection process. In our study example, we implemented procedures for collecting large numbers of Twitter user IDs' related interconnected users, and separate processes for collecting additional metadata (as needed for identifying users that we wished to examine further). The network data (i.e., edge files) were stored separately from node metadata (e.g., user names, follower or friend counts, profile descriptions, annotated variables) and our analysis did not require the linking of these two data types. However, there are analytic approaches where this might be advantageous (e.g., to establish network homophily). In such cases, it is ideal to limit the amount of combined data to only what is strictly required.

Results: Reporting results that could be potentially sensitive should be limited to aggregated data (e.g., frequencies and summary statistics) or general excerpts from quotes (e.g., not direct quotes which may be searchable on the Twitter platform). There is a primary risk of re-identifying participants by means of quotes from their posted content. While our case study is based on Twitter, each social media platform has different search algorithms which can influence what results are returned, and in what order. For example, general searches that include geographic filters will implicitly provide location data in the results; however, Twitter and Instagram have different methods of managing search preferences (i.e., how the location of the “searcher” is considered and prioritized when displaying results). This suggests that extra caution must be taken even when searches—and the results—are constrained by country, subject, or other criteria. In our example, the 2nd degree accounts were discovered based on a user action (i.e., following a cancer-

related account), but additional qualitative analyses were conducted in order to confirm characteristics potential cancer-related individuals. It may be feasible to directly infer health conditions, such as being affected by cancer, using a combination of network characteristics and available meta-data. This presents a particularly serious ethical concern where individuals' personal health status could be disclosed to unintended parties.

In the absence of clear and consistent guidelines by ethical review bodies, the decision of whether to conduct a network study using publicly available social media data will often come down to weighing the risks and the beneficence of the study itself, with the onus placed on a research community that often lacks sufficient ethical training or consensus. When making ethical decisions, researchers must balance the rights of subjects (as social network users, as research participants, as people) with the social benefits of the research itself. Guidelines, such as from the Association of Internet Researchers, provide a set of general principles and a set of questions to help inform a process of ethical self-reflection to help researchers grappling with this balance between the potential benefit of a research protocol and its potential risks. And applying Nissenbaum's theory of contextual integrity is useful to guide researchers' attentiveness to the normative bounds of how information flows on a particular social network or community under study. Yet, we must acknowledge that assessing the ethics of a particular research project is inherently complex, and ethical decision making is eventually dependent on a researcher's individual conscience, fundamental world view, academic and political environment, and disciplinary training—and even more so in Internet research, where there are few established ethical rules or policies.

This weighing of the value of research versus subject risks may lead to suboptimal results, as Zimmer and Kinder-Kurlanda (2017) note: “ethically-informed research practices come out of processes of deliberation and decision making under great uncertainty, which often may go wrong or seemingly force us towards less-ideal options” (p. 303). The adoption of blanket rules protecting subjects—such as a rule that no tweets should ever be collected without consent to protect users' privacy—could prevent valuable research that would benefit public welfare. Similarly, only reporting aggregated—or simulated—data will lead to challenges for ensuring the validity and reproducibility of research studies. At the same time, researchers cannot use positions that “the data is already public” or “consent was waived by the IRB” as absolute protections from potential ethical concerns.

While the current study focuses on data from the Twitter social media platform, other platforms where users interact around various health topics might lend to similar research approaches and ethical considerations. For example, networks of cancer-affected users can be identified via membership in relevant Facebook groups (Gage-Bouchard et al., 2017), and individuals can be observed networking with others to obtain support on platforms such as YouTube and Instagram (Struck et al., 2018). Further, several condition-specific online communities such as Cancer Survivors Network or PatientsLikeMe might provide similar types of network data (Zhang et al., 2016).

The concerns and uncertainties we identify in this paper are not meant to paralyze network researchers, but rather, should become a warning of the complexities of addressing the ethics of research in the context of social networks and health information. If the study necessarily includes some risk to identifying and reporting individuals' health status, researchers are urged to pursue with an abundance of caution.

Declaration of Competing Interest

The authors have no conflicts of interest to disclose.

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