Version of Record: https://www.sciencedirect.com/science/article/pii/S1551741120306665
Manuscript_d701e9f273b2d4e5c8c4ddac7554eb31

Evaluating Survey Consent to Social Media Linkage in Three International Health Surveys

Zeina N. Mneimneh[a]
[a]University of Michigan, USA
e-mail: zeinam@umich.edu
Corresponding Author

Colleen McClain[a]
[a]University of Michigan, USA
e-mail: camcclai@umich.edu

Ronny Bruffarets[b]
[b]KU Leuven, Belgium
e-mail: ronny.bruffaerts@uzleuven.be

Yasmin A. Altwaijri[c]
[c]King Faisal Specialist Hospital and Research Centre
e-mail: yasmint@kfshrc.edu.sa

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Introduction

The use of social media among the US general population has been increasing over time.[1] According to a telephone survey conducted by the Pew Research Center, the percent of US adults who reported using social media in 2019 ranged from 11% for Reddit, 22% for Twitter, 37% for Instagram, 69% for Facebook, to 73% for YouTube. The "real time" and organic nature of the data shared by users of these platforms have provided researchers an unprecedented opportunity to investigate human behaviors and attitudes in a cost-effective manner.[2]

Twitter, in particular, provides publicly available and accessible data to researchers. Sinnenberg et al.[3] systematically reviewed 137 published articles that used Twitter for health-related research between 2010 and 2015 and found that there was a two-fold increase in such publications each year. The most commonly studied topics were in the fields of public health (22%), infectious disease (20%), behavioral medicine (18%) and psychiatry (11%). While the public and accessible nature of the data are strengths of this platform for health researchers, the lack of clear understanding of how these organic data are generated and who is represented in a specific sample of tweets pose challenges for interpretation of findings and obstacles to their inference and replication.[4] Most researchers are aware that Twitter users do not represent the general population. Twitter users are younger, more highly educated, and wealthier than the general adult US population.[1] A more notable challenge is that the majority of tweets generated in the US come from a small fraction of the users.[5]. Thus, who is represented in a specific sample of tweets might vary further depending on the topic and time of discourse. Conducting research that sheds light on the data generation process, the type of information shared, and by whom it is shared is essential for advancing health-related research that is based on digital trace data such as Twitter.

One promising line of research that adds to the understanding of health-related data shared on Twitter is that which links multiple sources of data together. Stier et al.[6] provide a review on the opportunities and challenges of linking digital trace data to survey data. One essential premise of this research is that information available from source A can be leveraged to provide added value to source B, enhance the utility of B, and shed some light on B's data properties.

When linkage is carried out at an individual level—meaning an individual's data from source A, such as a survey, is directly or indirectly linked with that same individual's data from source B, such as Twitter posts—researchers need to obtain the respondent's consent, offering the opportunity for the respondent to decline such linkage request. This is especially essential in the case of Twitter data, where it is rare that users self-disclose important personal attributes (such as age, race, political affiliation, etc…) to the public. In this case, linking public Twitter data to user reported data from a different source may lead researchers to gather and learn added information about the user that the user might not have intended to share. While there continues to be a debate about whether using public information such as social media data requires the respondent's consent, we believe that when one source of information (even if it is public) is linked to another source of information, consent is needed. Zimmer (2010)[7] discusses a case study that highlights emerging challenges of engaging in research that uses facebook data without users' consent including challenges of data dissemination. A more recent publication by Sloan, Jessop, Baghal, and Williams (2019)[8] also provides useful insights into the importance of informed consent, and the complexity of disclosure, security and archiving of Twitter data when used for research purposes.

When requesting consent to link multiple data sources, not every individual will grant their consent. Lower rates of linkage consent could jeopardize the value of the combined data, if the size of the consented sample is small or biased to certain groups of individuals. Given these potential problems, investigating factors that affect granting consent to link Twitter data to other sources of data is valuable for exploring potential consent biases and designing consent requests that will improve the richness of the combined data set while adhering to proper ethical research practices.

The literature on consenting survey respondents to provide their Twitter handles and agree to link their Twitter public data to survey data is very limited. [8] To the authors' knowledge, there are only three publications that report on such actual consent (rather than hypothetical or willingness to consent) and provide some information on the characteristics of consenters. The rates of consent to link range from 24% to 90% using different samples, populations, modes, and consent languages. The highest rate of consent, 90%, was recently reported by Wocjik and Hughes[5] who conducted a web survey asking all active members of a US nationally representative online panel with an active Twitter account to provide their Twitter handles. All remaining reported rates are less than 50%. Also using a web survey, Henderson et al. [9] asked a non-probability sample of US residents to consent for downloading their Twitter data after logging into their account from the survey instrument. Of those who had a Twitter account, 25.7% consented. In the UK, Al Baghal et al.[10] asked respondents in three different studies to consent to link survey data to their Twitter public data. The first study was on a face-to-face national probability sample of the adult British population, in which the consent rate among Twitter users was 36.8%. The 2 remaining studies were also among the adult British population but one was among a probability-based panel and the other was among a longitudinal household study. In both of those studies, respondents who were surveyed by an interviewer whether by phone or face-to-face had higher consent rates, 34.4% and 40.5%, compared to those interviewed by web, 26.2% and 24.3% respectively. The lower rates in web surveys, reflect similar findings on data linkage such as those related to administrative records[11], highlighting the importance of investigating respondent characteristics associated with consent when interviewers are not present to address respondents' questions or concerns.

Both Henderson et al[9] and Al Baghal et al[10] provided demographic information on respondents who consented to link their survey data with their Twitter data. In general, US consenters seem to be similar to the overall sample of Twitter users on education, income, race, and gender but slightly younger.[9] In the UK study, controlling for education, employment status, income, and participation in the earlier survey waves, only in one of the studies, males and younger respondents were more likely to consent.[10]

Thus, in general, the rate of consenting to link survey data to Twitter public data is low. With limited work in this area, further research is needed to determine what characteristics are associated with the decision to link. While the literature lacks a linkage framework that guides researchers interested in linking survey data with Twitter public data specifically, several potential frameworks exist for consenting to link survey data with administrative data.[12,13] Factors that are discussed by Sakshaug et al.[13] and Beninger et al.[14] and that may be applicable to Twitter consent linkages include characteristics of the individual such as his/her psychographics, acquiescence tendencies, ability to comprehend the consent request, relevance of the task, privacy concerns, and experience with the organization collecting the data. Social environment-related factors could also play a role and include overall attitudes towards the type of social media being linked to and one's level of trust; in addition to survey design factors such as the consent language, placement, and mode.

While there are a multitude of factors identified in administrative data record linkages literature that could be applicable to Twitter linkage, in this paper we specifically focus on 1) individual level factors that could be correlated with consent to provide Twitter handles for linking survey data with Twitter public data (thereafter referred to as consent to link), and 2) whether consenters and non-consenters differ on health-related outcomes.

Methods

This paper uses data from three case studies that collected different types of information related to respondent characteristics, health measures, and social media use. While these studies were not originally designed to investigate factors associated with consent to link the survey data with Twitter public data, collectively they provide a valuable opportunity to investigate respondent level factors that could be correlated with such consent and they advance the limited body of literature on this topic.

The design and implementation protocol for all three studies was approved by the Institution Review Board (IRB) of the principal investigator's organization: KU Leven University (case study 1), University of Michigan (case study 2), and King Faisal Specialized Hospital (case study 3). In each case, the specific consent language used was determined by the researchers and the IRB requirements, resulting in variation across the case studies. In general, the appropriate consent language for collecting new forms of data such as social media is the subject of current debate.[7,8,14]

In each of the three case studies, survey respondents who self-identified as Twitter users were asked for consent to link their Twitter public data to their survey data. Respondents who consented were asked to report their Twitter handles. Those who did not consent were not asked for their Twitter handles as no Twitter data were to be collected on these respondents. Table 1 summarizes the key features of each survey, and Table 2 the corresponding consent language.

Study Design, Sample, and Participants

Case Study 1: College Student Population in Belgium

All new and returning undergraduate students who were enrolled in Fall of 2018 at KU Leuven University were invited to participate in the Leuven College Survey (LCS), which is part of the WHO World Mental Health Surveys International College Student Project.[15] LCS is a web administered survey that focuses on affective disorders and suicidality among students. At the time of the fielding, respondents were new first-year students who never participated in LCS (i.e. baseline); completed one previous baseline assessment of the same survey (i.e. follow-up on respondents); or were non-respondents in previous waves and were invited to participate for the first time (i.e. follow-up on non-respondents). Because non-respondents from previous waves may differ significantly from those who were responding for the first time or for their first follow up, they were excluded from the paper's analysis. The response rate for first time respondents was 24.7%, and 46.7% for follow up respondents. At the end of the survey, respondents were asked about their Twitter use, and users were asked for consent to link their survey data with their Twitter public data. The consent language used in provided in Table 2.

Case Study 2: Adult Population in the United States

A random sample of US households was selected using address-based sampling (ABS) and invited to participate in a web survey titled "The National Survey of Well-being". Respondents were initially contacted via mail and were provided with a link to access the survey online. The letter specified that the survey should be completed by the adult (18 years or older) in the household with the next birthday. The survey included questions on people's behaviors and attitudes related to health, race and gender, politics, and finances. The study was fielded between late 2017 and early 2018 with a response rate of 7.0%. At the end of the survey, respondents were asked whether they use Twitter and for their consent to link their Twitter public data and their survey responses (Table 2).

Case Study 3: Adult Population in the Kingdom of Saudi Arabia

Consent to link Twitter public data to survey data was also included in a mental health study that was conducted in the Kingdom of Saudi Arabia (KSA) referred to as the Saudi National Mental Health Survey.[16] A national multi-stage area probability sample was selected for the main study[17]. The decision to collect Twitter handles from survey respondents was made later in the study and only administered in 7 out of the 11 administrative areas. The questionnaire was translated into Arabic using a team approach and following survey translation best practices.[18] The questionnaire was administered face-to-face by interviewers who were gender-matched to respondents. Within each selected household, 2 respondents between the ages of 15-65 were selected, 1 random female and 1 random male. Only Saudi citizens who spoke Arabic and who were between the ages of 16-65 were eligible for this study. The survey was fielded between 2013 and 2016 with an overall response rate of 61%.[a] Respondents who reported being Twitter users were asked for permission to link their survey data with their public Twitter data using the consent language provided in Table 2.

While all of three case studies consented respondents to data linkage, they were not systematically designed to investigate predictors of consent. Thus predictors of consent and health measures collected in each of these case studies varied as described below.

Measurement and Variables

A series of questions asked in each survey were used to predict consent, and are described in depth for each case study below.

Case Study 1: College Student Population in Belgium

Respondents who completed the web survey were asked to report on their age (in years), their gender (female, male, transgender, other), whether they use Facebook, Twitter, Instagram, Snapchat, Reddit, and/or LinkedIn, frequency of using Twitter among Twitter users (more than once a day, once a day, several times a week, once a week, less than once a week, don't know, prefer not to answer), and ways in which the respondent used Twitter (read tweets, retweet, tweet about self, family, or friends, other). Respondents were also asked a series of questions about their physical and mental health including: how they would rate their overall physical health (scale of 1 to 5), days out of work or interference with usual activity in the past year because of physical or mental health problems (reported as number of days), symptoms related to mood disorder, anxiety disorder , impulse control disorder , eating disorders , alcohol use disorder , and whether the respondent has ever had any suicidal ideation, plan or action. For the purpose of analysis, these measures were used to create the following variables that were used for investigating association with consent to link. Age was used as a continuous variable, gender was coded as female vs. male, an index of social media use was created with 3 categories (0-3 social media sites used, 4, or 5), frequency of using Twitter among Twitter users (daily, more than once a week but less than daily, less than once a week, and don't know/refusal), and type of Twitter use (tweeting, retweeting, reading tweets or other type of use only, and did not report on use). In addition, having a high risk for alcohol use disorder was included in the model given its potential to serve as a proxy for willingness to share sensitive information. All health measures, except the physical health rating scale, were coded as whether the respondent fulfilled criteria for the health condition or not.

[a] The long field duration was caused by several interruptions in the data collection because of weather conditions and funding cuts.

Case Study 2: Adult Population in the United States

Respondents were asked about their: age (in years), gender (male or female), marital status (married, separated, divorced, widowed, never married), highest level of education (less than high school, high school graduate/GED, some college but no degree, associate degree, bachelor's degree, graduate or professional school), income category (divided into sixteen brackets ranging from <5,000 USD to 150,000 USD or more per year), race (white, black or African American, Asian, Native Hawaiian, other), ethnicity (Hispanic or not), religious identification (Protestant, Catholic, Jewish, none, other), spirituality (not spiritual at all, slightly spiritual, moderately spiritual, very spiritual), and adult household size (the number of adults in their household). Respondents were further asked about frequency of engagement in 15 helping behaviors during the past 12 months. Some of these measures were grouped further to avoid categories with a small number of cases while allowing for meaningful variation in responses. The reduced measures were: marital status (currently married, previously married, never married), education (high school or less, some college or more), income (reported vs. missing, as a proxy for willing to provide private information), race (white, black, others), religious affiliation (Protestant, Catholic, Jewish or Others, none), spirituality (not spiritual at all, slightly spiritual, moderately or very spiritual), and number of adults in the household (1, 2, 3 or more). Each of the 15 helping behaviors was coded into a binary indicator of whether or not the respondent had ever engaged in the behavior in the past year. Exploratory factor analysis was used to assign behaviors to two factors from which factor loadings were extracted for use in the analysis. Factor 1 included donating blood, giving food or money to a homeless person, returning money after getting too much change, doing volunteer work for a charity, giving money to a charity, giving directions to a stranger, and talking with someone who was down or depressed. Factor 2 included offering your seat to someone on a bus or public place, looking after a person's plants, mail, or pets while they were away, carrying a stranger's belongings, letting someone you don't know borrow something, helping someone outside of your household with housework or shopping, lending money to another person, and helping someone to find a job.

Respondents were also asked a series of health questions including their self-rated health (excellent, very good, good, fair, poor), and whether they have health insurance, have vision problems, walk or use a bicycle for at least 10 minutes continuously to get to and from places in a typical week, engage in other vigorous exercise in a typical week, have smoked 100 cigarettes in their life, have a health problem that requires the use of special equipment or a hearing aid, report their health is better, worse, or about the same as 12 months ago, have ever had 12 drinks in their life and, if so, how many drinks they had in a typical sitting, and have ever been told they had any of 9 health conditions by a doctor (hypertension, high cholesterol, heart disease, angina, a heart attack, asthma, an ulcer, cancer, or a seizure disorder). Questions about insurance, vision, walking, biking, exercise, and smoking were used as binary variables. Reporting a health problem that requires special equipment or hearing aids was considered as a disability and also analyzed as a binary variable. Finally, questions about drinking were coded to represent the number of drinks in a typical sitting (0 if never drank), and the 9 health conditions were summed and then coded into one measure grouping chronic conditions. Self-rated health and change in health were used as continuous variables.

Case Study 3: Saudi National Population

Respondents in the Saudi National Mental Health Survey were asked to report on a number of sociodemographic characteristics including age (in years), gender (male, female), marital status (married, separated, divorced, widowed, never married), education (highest number of education years) and number of household members (a complete list of household members). Since this was a face-to-face survey, information from the sampling frame was available on whether the address is in a rural or urban city or town. A series of questions related to Twitter use were also administered to investigate whether providing personal information on Twitter might relate to giving consent to link. These included whether or not the respondent: has a personal profile picture, geotags his/her tweets (always, sometimes, never, don't know how to use this feature, or mobile device does not have this feature), and reports his/her city or town in the public profile (yes, no, or not sure). In addition, questions related to frequency of reading tweets, retweeting or tweeting were asked with the following response options: daily, several times a week, once a week, less than once a week, or never. Some of these measures were subsequently categorized as follows: currently married vs. not; has high school diploma or less vs. some college or more; lives in a household with 1-4 members, 5-7, vs. 8 or more; and has a personal Twitter profile picture. Frequency of the different types of Twitter use was grouped into several times a week or more, once a week or less, and did not report.

Statistical Methods

For case studies 1 and 2, two types of models were run. The first was a logistic regression model predicting consent to link (yes vs. no). For the Belgian college student survey (cases study 1) the following were entered as predictors: age, gender, whether the respondent participated in the earlier wave or is a first-time respondent, number of social media sites used, frequency of Twitter use, type of Twitter use and whether the respondent was found to have a high risk for alcohol use disorder. For the US adult population survey (case study 2) predictors of consent included age, gender, marital status, race, Hispanic ethnicity, education level, household size, religious identification, spirituality, reporting income, and the two helping behavior factors.

The second set of regression models predicted each of the health outcomes in case studies 1 and 2 to test whether consenters and non-consenters differ on health outcomes, controlling for the predictors found to be significantly associated with consent to link in the first set of models. Depending on the functional form of the health outcome, logistic (for binary outcomes), linear (for continuous outcomes), or Poisson (for count outcomes) models were used.

For case study 3, (Saudi Arabia population study), given that the sample of Twitter users was small (n=188), regression models were not estimated. Weighted bivariate analysis was conducted to test the association between each of socio-demographic characteristics and Twitter use variables, with consent to link.

Analyses of the Twitter sample were restricted to respondents who provided information on all of the variables. Only 1.4% and 2.4 % of Twitter users in case studies 1 and 2 (respectively) were excluded from analysis because of missing information on any measure included in the analysis. Analyses were conducted using SAS 9.4.

Results

Participants & Consent Rates

Rates of Twitter use ranged from 20% among US respondents (case study 2), 23% among KSA respondents (case study3), to 36% among Belgian college student respondents (case study 1). Among self-identified Twitter users, consent to link ranged from 24% in the Belgian web survey, 27% in the US web surveyed, and 45% in the KSA face-to-face survey (Table 3).

Descriptive Statistics

Tables 4-6 summarize the characteristics of respondents participating in each of the three surveys and how they compare to respondents who reported using Twitter (whether or not they consented to link).

College Student Population in Belgium: The overall undergraduate respondent sample and those who report using Twitter were found to be generally similar on age (18.7 and 18.6 years old on average) and gender (34.0 % and 31.7% are males), and the majority participated in the survey for the first time (67.1% and 72.1% respectively). In terms of being at high risk for alcohol disorder, a little over a third of the overall sample and the Twitter users screened positive (34.7% and 37.7%). As for social media use, only 8.9% reported being users of less than 4 sites, 72.1% use 4 sites, and 18.5% use all 5 sites inquired about. Looking closely at Twitter use specifically, 41.5% reported using Twitter daily, 19.0% reported using Twitter on a weekly basis but less than daily, and 35.6% use it less than weekly. Most Twitter users reported reading posts only (about 60.0%), 22.4% reported retweeting, and only 10.0% reported tweeting.

Table 4 here

US Adult Population Study: The composition of the total respondent sample and those who reported being Twitter users was similar on most of the sociodemographic and psychographic characteristics including gender, race, education, household size, religious identification, and helping behavior scores. However, Twitter users in the survey were younger (41.3 years old on average vs. 48.4 years), reported higher rates of not being married (36.8% vs. 25.4%), and were less spiritual (52.4% reported very or moderately spiritual vs. 61.8%) compared to the overall respondent pool.

Table 5 here

KSA Population Study: While the two household characteristics (household size and urbanicity) were generally the same between the overall sample and Twitter users, Twitter users in KSA were more likely to be males (56.0% vs. 49.8%), not currently married (57.7% vs. 41.2%), younger (29.8 years old vs. 34.5 years old on average), and have higher education (40.8% have at least some college vs. 23.8%). In terms of their pattern of use, the majority of Twitter users in the sample reported that they do not use a personal profile picture (85.3%), geotag their Tweets (86.3%), or include their city or town in their profile (or are not sure if they do, 58.5% combined). Moreover, the majority of Twitter users read posts several times a week (57.8%), a little less than a third re-tweet (30.9%), and 40.9% reported tweeting several times a week or more.

Table 6 here

Predictors of Consent

College Student Population in Belgium: Controlling for age, gender, and previous wave participation, social media use, frequency of Twitter use, and risk for alcohol use disorder were significantly associated with consent to link. Respondents who reported using Twitter daily, or more than once a week but less than daily, irrespective of the type of use, were more likely to consent than those who reported using Twitter less than once a week (ß= 1.126 and 0.844 respectively). Moreover, those who reported symptoms and were found to have a high risk for alcohol use disorder were more likely to consent than those did not report symptoms and scored low risk (ß=0.532).

Table 7 here

US Adult Population Study: Although no social media use measures were collected in the US adult population sample, a number of demographics and psychographic measures were available on respondents and were included in a model to predict consent to link. While the majority of these measures were not correlated with consent, respondents who reported lower education and being Jewish were less likely to consent compared to those with at least a college education (ß= -1.260, marginally significant) and those who reported no religion (ß= -0.972). Respondents with higher scores on the second helping behavior factor were marginally more likely to consent (ß= 0.329).

Table 8 here

KSA Population Study: While consenters and non-consenters were similar with respect to the majority of socio-demographic characteristics, a higher percentage of males (54.0%) than females (38.0%) consented to link their public Twitter data with their survey data. A pattern was also observed between a number of Twitter use measures and consent. Those who provided more information on Twitter, such as geotagging their tweets and reporting their town or city to their profile information, were more likely to consent than those who did not provide this information (56.0% vs. 43.3% and 53.7% versus 38.9%, respectively). Moreover, those who reported reading tweets or re-tweeting once a week or less were more likely to consent than those who did not report any use (57.8 % vs. 24.3% and 59.1% vs. 39.2% respectively). Given the smaller sample size, none of these differences reached statistical significance.

Table 9 here

Health Outcomes of Consenters vs. Non-Consenters

Figure 1 summarizes the association between consent to link and each of the health-related outcomes measures in the college student population in Belgium and the US adult population studies. Consenters and non-consenters were not found to be statistically different on any health measure from these two studies, controlling for covariates associated with consent.

Figure 1 here

Discussion

Understanding correlates of consent to link survey data with social media data is essential for guiding design protocols that will enhance the richness of the linked data while measuring the potential bias in the linked sample. Linked datasets (survey data and social media) can then be used to leverage the properties of one source to enhance the utility of the other. For example, by linking survey data to Twitter data, researchers can gain better insight into who is generating a specific pool of tweets, can assess the accuracy of prediction algorithms that use Twitter data against survey data (as ground truth), and can explore the measurement and representation properties of the data collected from social media.

This is the first paper that investigates a range of individual level characteristics and their association with consent to link survey data with Twitter public data. The consent rate estimates from each of the 3 case studies were found to be consistent with other publications. In the two case studies that used a web administered mode, one among college students in Belgium and the other among the US adult population, 24% and 27% of those who reported having a Twitter account consented to link. These rates are very similar to what have been published among other samples in the US (25.7% consented in Henderson et al's study[10]) and the UK (26.2% and 24.3% consented in Al Baghal et al's studies[11]) where web administration was also used. When interviewed through a face-to-face mode, 45% of respondents who reported having a Twitter account in the Saudi National Mental Health survey consented to link. This higher rate is also consistent with Al Baghal et al[11], who reported 36.8% and 40.5% consent rates among both British samples using a face-to-face interviewer mode. On one hand, the similarity of consent rates within a mode across samples and cultures is promising for replication and comparability especially in a Multinational, Multiregional, and Multicultural Contexts (3MC*).* On the other hand, while the higher rate of linkage consent in face-to-face surveys (compared to web mode) is not surprising given the role the interviewer plays in motivating respondents, the confounding of mode differences with language and cultures makes it difficult to isolate the source(s) of similarity or divergence in findings across study sites.

Moreover, in similar fashion as Henderson et al[10] and Al Baghal et al[11], socio-demographic characteristics in all of the three case studies were only minimally associated with consent to link. The two observed marginal differences were education in the US study and gender in the KSA study. In the US adult population study, respondents who did not have any college education were less likely to consent than respondents with at least some college education. While education was not associated with consent in Henderson et al.[10], this inconsistency in findings could be explained by the different types of sample employed. While Henderson et al.[10] conducted the study among a non-probability online panel in which respondents are used to taking web surveys and are paid for being part of the panel, the study described here was based on an address-based sample design that recruited a general population sample. Respondents who join opt-in efforts even within a given education group may be different along other dimensions that affect propensity to link compared to those interviewed in the general population study. Also observed but not significant was an association between gender and consent in KSA; while 54% of male respondents consented to link, only 38% of females consented. A similar gender difference was found by Baghal et al[11] in one of the three British samples studied. Whether this is driven by cultural differences in gender roles, gender specific privacy concerns, or different patterns of social media use are questions that remain open and that will benefit from future research.

Other than socio-demographics, two of the three case studies collected measures related to patterns of social media use and found that higher frequency of use and providing information about one's location—were associated with consent. While such associations have not been explored in the Twitter consent literature, other literature exploring consent to link administrative data, willingness to participate in mobile data collection tasks, and willingness to share GPS data have found similar associations. Beninger et al[13] note that the relevance of the task to the respondent can influence their decision to give consent for linking survey data with health administrative records. Others have found that intensive and frequent mobile device use was associated with increased willingness to participate in mobile data collection tasks (Wenz et al[19)] and to share GPS data (Elevelt et al[20]). It is possible that respondents who are more engaged in the use of social media find the task more relevant to them, are more familiar with what is shared on these platforms, and therefore are more motivated to consent.

Turning to the relationship between providing personal information and consent, respondents in Saudi Arabia who reported providing information about their location through their profile or geocoding their tweets were 13- 15 percentage points more likely to consent to link their survey data with their Twitter public information than those who did not; however the differences were not significant given the small sample size. It may be that publicly sharing potentially identifying information on Twitter and consenting to link are both driven by an underlying propensity of sharing information about oneself with others. This underlying propensity could also explain why respondents who endorsed symptoms of alcohol disorder in the Belgian college student survey were also more likely to consent. These respondents might be less concerned about sharing sensitive or identifying information in general. Future research that explores this mechanism further would be valuable.

Finally, respondents in the Belgian college sample and the adult US sample who consented to link did not differ from non-consenters on any of the health measures. This finding is promising for researchers conducting health related studies using linked data from surveys and Twitter, as linkage does not seem to create bias toward a more or a less healthy group of respondents. Such finding would benefit from future replication among different samples and populations.

Limitations

Findings from these case studies should be considered with the following limitations in mind. First of all, none of these studies were initially designed to investigate predictors of consent to link survey data with Twitter public data, nor they were part of the same 3MC initiative aimed to enhance comparability. Thus, using a standard set of individual-level predictors (other than a simple set of socio-demographics) across the three cases studies, or isolating differences related to culture, language, or country differences were not feasible. Moreover, exploring design factors such as the survey mode, placement of the request within the survey questionnaire, and language of consent, were not possible. Future investigations of informed consent that vary the language related to potential concerns, secure data storage, and risks of disclosure would be important for health-related research that uses publically available data which could include potentially identifiable information such as social media. Second, none of the case studies oversampled Twitter users and achieved a sample size large enough to determine whether some of the seemingly large differences between consenter and non-consenters were significant. Third, all Twitter use and pattern of use variables were self-reported; Henderson et al.[10] found that while there is a correlation between self-reported measures and actual behaviors, there are discrepancies between the two that vary by the type of Twitter activity. While some of the Twitter self-reported measures in the current case studies were found to be correlated with consent to link, others were not. Whether these associations (or the lack of them) hold when using actual behavioral measures is an open question that calls for further exploration. Finally, the three case studies were based on probability samples that were designed to represent KU Leuven college students in Belgium, the US adult population, and the KSA adult population. However, given that the sample sizes were not maximized to investigate Twitter users in each of these populations, the estimates from these cases studies suffer from large margins of errors.

Conclusions

Results from the three case studies replicate some of the recent findings on consent to link survey data with Twitter public data. Consent rates from two of the three case studies that used a web administered mode ranged from 24% to27%. The face to face study in KSA had a consent rate of 45%. Moreover, consistent with the limited social media consent literature, respondents' socio-demographics were minimally associated with consent. However, the current case studies expand consent predictors to more than socio-demographics. The nature and frequency of Twitter usage, along with the amount of information shared, emerged as an important predictor of consent. Finally, consenters and non-consenters were found to be similar on a varied set of health outcomes, a finding that is promising for heath researchers who plan to link survey data with Twitter data.

Declaration of interest statements

The authors declare that they have no conflict of interest in relation to the work covered in this paper.

Funding:

Case Study 1: The KU Lueven College Student Study was funded by Research Foundation Flanders (1114717N, 1114719N), Koning Boudewijnstichting (2014-J2140150-102905), and Diepensteyn Foundation (2018-LUF00070).

Case Study 2: The adult population study in the United States was funded by the National Science Foundation, Division of Social and Economic Sciences, grant number 1259985

Case Study 3: The Saudi National Mental Health Survey (SNMHS) is funded by Saudi Basic Industries Corporation (SABIC), King Abdulaziz City for Science and Technology (KACST), Abraaj Capital, Ministry of Health (Saudi Arabia), and King Saud University. Funding in-kind was provided by King Faisal Specialist Hospital and Research Center, and the Ministry of Economy and Planning, General Authority for Statistics. None of the funders had any role in the design of the study, data analysis, interpretation of results, or preparation of this paper. The SNMHS is carried out in conjunction with the World Health Organization World Mental Health (WMH) Survey Initiative. We thank the staff of the WMH Data Collection Coordination Centre in the Survey Research Center at University of Michigan and the WMH Data Analysis Coordination Centre in the Department of Health Care Policy at Harvard Medical School for assistance with design, instrumentation, fieldwork, and consultation on data analysis.

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Table 1. Study design summary.

#	Country	Study name	Target population	Sampling method	Survey mode	Survey language	Health Topic	Response rate
1	Belgium	Case Study 1: Leuven College Survey (LCS)	New and returning undergraduate students enrolled in Fall 2018 at KU Leuven University	All new and returning students in Fall 2018 were asked to participate	Web	English or Dutch	Mental health – affective disorders and suicidiality among students	24.7% for new respondents; 46.7% for follow up respondents
2	U.S.	Case Study 2: The National Survey of Well-being	US adults (18 and older)	Address-based sampling	Web	English	Behaviors and attitudes related to general health,	7.0%
3	Saudi Arabia	Case Study 3: Saudi National Mental Health Survey	Saudi citizens between the ages of 15 to 65 who can speak Arabic	Multi-stage Area probability sampling	Face-to-Face	Arabic	Mental health	61.0%

Table 2. Consent language.

#	Country	Consent language
1	Belgium	Case Study 1: As part of this project, the research team would like to understand how survey responses relate to social media content. To help us explore this, we would like to ask your permission to collect your public Twitter profile and tweets and analyze them for research purposes. Your consent is completely voluntary and your social media information will be kept confidential and stored in a password protected database. Do we have your permission?
2	U.S.	Case Study 2: We are interested in learning whether people's Twitter feed is informative of demographic characteristics and combining Twitter data with the survey data will help us study the relationship. Although we might get identifiable information about you from your Twitter account, we will not reveal your identity to anyone outside the research team and we will not report the information from this survey in a way that your identity would be revealed. We will not use the information from your Twitter account for any other purposes. For research purposes, would you allow us to combine information from your Twitter feed with responses from this survey?
3	Saudi Arabia	Case Study 3: We appreciate the time you have taken to answer the survey questions. As part of this survey, we would like to ask your permission to link your public Twitter information to your interview information. This information will be kept confidential and will only be used for academic purposes at an aggregate level. That is no information will be disclosed on any individual respondent in any research report or publication. Your consent is completely voluntary. Your permission will be extremely valuable for understanding how people are using Twitter. Do we have your permission?

Table 3. Consent rates.

	Total n	% Twitter users (unweighted n)	% of Twitter users consented
1	1615	35.6% (n=575)	23.8% (n=137)
2	1846[a]	20.0% (n=370)	27.0% (n=100)
3	1048	23.0% (n=188)	45.0% (n=95)

a 42 respondents did not report their Twitter status bringing the sample down to 1846 from 1888

Table 4. **KU Leuven College Student Sample Descriptive Statistics**

	% of Respondents (N=1615)[a]	**% of Twitter Users (N=562)[b]**
Categorical Sociodemographics		
Gender		
Female	65.4% (1053)	68.3% (384)
Male	34.6% (557)	31.7% (178)
Survey Cohort		
Baseline	67.1%(1083)	72.1% (405)
Follow Up	32.9% (532)	27.9% (157)
Social Media Use Variables		
Social Networking Sites Used		
0-3		8.9% (50)
4		72.6% (408)
5		18.5% (104)
Frequency of Twitter Use		
Daily		41.5% (233)
More than once a week/less than daily		19.0% (107)
Less than once a week		35.6% (200)
Don't know/missing		3.9% (22)
Twitter User Type (Recoded)		
Tweets		10.0 % (56)
Retweets		22.4% (126)
Reads only / other no use		59.6 (335)
No use reported		8.0% (45)
Reported Sensitive Information		
Any AUDIT alcohol risk		
Any	34.7% (561)	37.7% (212)
None	65.3 % (1054)	62.3% (350)
Continuous sociodemographics	**Mean (SD) [Min, Max]**	**Mean (SD) [Min, Max]**
Age	18.7 (0.9) [16,25]	18.6 (0.8) [18, 23]

[a] might vary for each variable depending on missing information on each variable. Rates of missing information <less than 1%. AUDIT=Alcohol Use Disorder Identification Screen

[b]= The sample was restricted to respondents have observed information on all variables included in the table bringing the sample of Twitter users down from 575 to 562. This approach is used to keep the sample constant across this descriptive table and logistic regression model in Table 4

Table 5. Adult National US Sample Descriptive Statistics

Variable	% of Respondents (N=1888)[a]	% of Twitter Users (N=361)[b]
Categorical Sociodemographics		
Gender		
Female	56.6% (1062)	54.6% (197)
Male	43.4% (813)	45.4% (164)
Marital Status		
Married	55.6% (1042)	49.9% (180)
Separated/divorced/widowed	19.0% (357)	13.3% (48)
Never married	25.4% (476)	36.8% (133)
Race		
White	81.4% (1510)	76.7% (277)
Black	5.9% (110)	7.4% (27)
Other	12.7% (236)	15.8% (57)
Hispanic		
Yes	7.9% (147)	12.5% (45)
No	92.1% (1723)	87.5% (316)
Education		
High school or less	13.3% (248)	7.8% (28)
Some college or more	86.7% (1624)	92.2% (333)
Household size		
1	25.2% (475)	22.2% (80)
2	57.1% (1078)	57.6% (208)
3+	17.7% (334)	20.2% (73)
Religious Identification		
Catholic	22.2% (409)	24.1% (87)
Jewish or Other	25.8% (474)	21.1% (76)
Protestant	25.7% (473)	23.0% (83)
None	26.3% (485)	31.9% (115)
Spirituality		
Very or moderately spiritual	61.8% (1154)	52.4% (189)
Slightly spiritual	24.1% (451)	30.2% (109)
Not spiritual at all	14.1% (263)	17.5% (63)
Income		
Answered	93.5% (1765)	96.4% (348)
Missing	6.5% (123)	3.6% (13)
Helping Behaviors		
Factor 1	2.4 (0.7) [0,3.3]	2.4 (0.6) [0,3.1]
Factor 2	1.5 (0.9) [0,3.1]	1.6 (0.8) [0,3.1]
Continuous sociodemographics	**Mean (SD) [Min, Max]**	**Mean (SD) [Min, Max]**
Age	48.4 (17.3) [18,99]	41.3 (14.9) [18,85]

[a] might vary for each variable depending on missing information on each variable. Rates of missing information range from 0.7%-2.5%

[b]= The sample was restricted to respondents have observed information on all variables included in the table bringing the sample of Twitter users down from 370 to 361. This approach is used to keep the sample constant across this descriptive table and logistic regression model in Table 5

Table 6. Kingdom of Saudi Arabia Mental Health Study Descriptive Statistics

Variable	Weighted % of Respondents N=1048 (Unweighted n)[a]	Weighted % of Twitter Users N=188 (Unweighted n)
Categorical sociodemographics		
Gender		
Female	49.8% (547)	56.0% (99)
Male	50.2% (501)	44.0% (88)
Marital Status		
Currently Married	58.8% (719)	42.3%(104)
Currently Not Married	41.2% (329)	57.7%(84)
Education		
High school or less	76.2% (807)	59.2%(110)
Some college or more	23.8% (241)	40.8%(78)
Household size		
1-4	22.0% (315)	22.2%(60)
5-7	40.5% (420)	35.1%(78)
8+	37.5% (313)	42.7%(50)
Residence Location		
Urban	76.0% (781)	72.9%(148)
Rural	24.0% (267)	27.1%(40)
Twitter Use Variables		
Profile Picture		
User's picture only		14.7%(29)
Other pictures		85.3%(159)
Use Location Tag		
Yes		13.7%(31)
No		86.3%(157)
Profile has City or Town		
Yes		41.5%(78)
No		56.3%(105)
Not sure		2.2%(5)
Frequency of Reading Tweets		
Did not report		18.1%(31)
Once a week or less		24.1%(51)
Several times a week or more		57.8%(106)
Frequency of Retweeting		
Did not report		38.6%(75)
Once a week or less		30.5%(57)
Several times a week or more		30.9%(56)
Frequency of Tweeting		
Did not report		24.4%(53)
Once a week or less		34.7%(64)
Several times a week or more		40.9%(71)
Continuous sociodemographics		
		Mean (s.e.) [Min, Max]
Age	34.5 (0.53)[18,65]	29.81 (0.98) [18,63]

Table 7. Logistic Model predicting Consent to Twitter by Socio-demographics and Social Media Use in KU Leuven College Survey, N= 562

Predictors	Coefficient (standard error)
Age	-0.202(0.183)
Gender (ref=male)	
Female	0.051(0.248)
Survey Cohort (ref=Baseline)	
Follow Up	0.355(0.290)
Social Networking Sites Used (ref=0-3 sites)	
4	0.140(0.425)
5	0.919(0.452)*
Frequency of Twitter Use (ref=less than once/week)	
Daily	1.126(0.289)**
More than once a week but less than daily	0.844(0.320)**
Don't know/missing	-0.260(0.787)
Twitter User Type (Ref=read only/other use)	
Tweets	0.223(0.338)
Retweets	0.084(0.261)
No use reported	-0.427(0.576)
Any AUDIT alcohol risk (ref=none)	
Any	0.532(0.215)*

† p-value between 0.05-0.08, *p-value <0.05, **p<0.01
AUDIT=Alcohol Use Disorder Identification Screen

Table 8: Logistic Model predicting Consent to Twitter by Socio-demographics and Helping Behavior in US Adult Population Sample (N=361)

Predictors	Coefficient (standard error)
Age	-0.002(0.012)
Gender (ref=Male)	
Female	0.205(0.255)
Marital Status (ref=Never Married)	
Married	0.429(0.376)
Separated/divorced/widowed	0.156(0.483)
Race (ref=white)	
Black	0.236(0.498)
Other	-0.229(0.417)
Hispanic (ref=non-Hispanic)	
Yes	0.621(0.421)
Education (ref= Some college or more)	
High school or less	-1.261(0.658) †
Household size (ref=1)	
2	0.175(0.387)
3+	-0.248(0.477)
Religious Identification (ref=None)	
Catholic	-0.076(0.374)
Jewish or Other	-0.972(0.422)*
Protestant	-0.261(0.393)
Spirituality (ref= Not spiritual at all)	
Slightly spiritual	0.487(0.417)
Very or moderately spiritual	0.074(0.439)
Income (ref=answered)	
Missing	-0.153(0.717)
Helping Behaviors	
Factor 1	-0.044(0.255)
Factor 2	0.329(0.184) †

† p-value between 0.05-0.08, *p-value <0.05

Table 9. Distribution of Consent Status by Sociodemographics and Twitter Use : Kingdom of Saudi Arabia Mental Health Study, N=188

Variable	**Consented** **Weighted % (un-weighted n)**	**Chi-square test**
Categorical sociodemographics		
Gender		
Female	38.0% (99)	
Male	54.0% (89)	2.899†
Marital Status		
Currently Married	50.2% (104)	
Currently Not Married	41.3% (84)	0.835
Education		
High school or less	48.0% (110)	
Some college or more	40.8% (78)	0.537
Household size		
1-4	50.2% (60)	
5-7	43.6% (78)	
8+	43.6% (50)	0.337
Residence Location		
Urban	45.1% (148)	
Rural	44.9% (40)	0.000
Twitter Use Variables		
Profile Picture		
User's picture only	44.0% (29)	
Other pictures	45.2% (159)	0.008
Use Location Tag		
Yes	56.0% (31)	
No	43.3% (157)	1.018
Profile has City or Town		
Yes	53.7% (78)	
No/Not Sure	38.9% (110)	2.048
Frequency of Reading Tweets		
Did not report	24.3% (31)	
Once a week or less	57.8% (51)	
Several times a week or more	46.2% (106)	5.233†
Frequency of Retweeting		
Did not report	39.2% (75)	
Once a week or less	59.1% (57)	
Several times a week or more	38.5% (56)	3.509
Frequency of Tweeting		
Did not report	40.6% (53)	
Once a week or less	48.4% (64)	
Several times a week or more	44.9% (71)	0.355
Continuous sociodemographics	**Mean (s.e.)**	t-test
Age		
Consented	30.12 (1.05)	-0.39
Not Consented	29.56 (1.01)	

† p-value between 0.05-0.08, *p-value <0.05

Figure 1: Regression Coefficients with 95% Confidence Interval for Consent to Link to Twitter with each of the Health Outcomes in KU Leuven College Study and US Adult Population Study