BEHIND THE COMPUTER SCREEN:
WHAT IRB PROFESSIONALS REALLY THINK ABOUT SOCIAL MEDIA RESEARCH

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Abstract

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Introduction: Researchers are increasingly incorporating social media into studies. Thus, Institutional Review Board (IRB) reviewers are called to review this social media (SoMe) research, often without formal training or clear expectations of what practices in SoMe environments present increased risks for research participants. The purpose of this study is to explore the views and experiences of IRB and ethics professionals' with SoMe research.
Methods: For this qualitative interview study we used purposeful sampling to identify IRB members and ethics professionals with at least six months of cumulative experience reviewing the ethical conduct of research. All interviews were conducted by a trained graduate student and recorded with verbatim transcription. Open-ended questions gathered information about subjects' personal use, attitudes and beliefs in regards to SoMe research. A combination of inductive and deductive qualitative analyses was conducted to identify themes and categorical variables. Data (30%) was double coded to ensure accuracy.
Results: IRB/ethics reviewers were recruited from academia (65%), private (17%), government (15%), and medical (2%) organizations. Key responses included a lack of consensus about whether or not SoMe presented new privacy risks, demonstrated in two example quotes: "I mean if it's public and you haven't put it behind certain privacy settings then it's not confidential at all." versus "Just because you posted something … (that) has been bought by another company and has made all those things public…the researcher has to really think about the true original intent.". Three major themes arose from the data: 1) assumptions about potential ethical risks when using SoMe in research studies; 2) responsibility of keeping SoMe users informed of these risks; and 3) framing of privacy risks within the context of SoMe settings
Conclusions: Findings may influence future policies, training, staffing and procedures by IRBs and research institutions as they face a digital era of science with evolving ideas about what SoMe ethics are and how best to uphold them.

Introduction

Social media (SoMe) continues to play a role in most Americans' daily lives, more so than ever before. This is clearly demonstrated by the current number of users, with more than a billion on Facebook and 310 million on Twitter (1, 2). As of 2015, approximately 65% of adults in the U.S. used SoMe (3). The utilization of SoMe has expanded from socializing to political action, education, and tracking of one's own health and financial data. Today, 64% of all adults also own smartphones. These devices integrate social media applications in design and function. New mobile devices offer a high level of social capability, like Amazon's Echo and Google's Home, are hitting the market with the dual purpose of collecting data on lifestyle and behavior patterns for marketing intelligence. Amazon, Microsoft, and other technology companies are forging new partnerships with the public sector in the interest of data sharing (4).

It makes sense then that researchers would want to capitalize on this unprecedented access to large sets of personal information. Professor Jeffrey Hancock, one of the lead investigators of the infamous Emotional Contagion Experiment at Cornell University, has argued that the ethics of emerging technology, including SoMe and big data, may be the issue of our time (5). Pharmaceutical and health science industries see SoMe as future terrain for participant recruitment and retention in clinical trials (6). How researchers will use SoMe in the future will surely adapt as current tools like application programming interfaces offer advanced ways of downloading and manipulating big data from SoMe (7). The topics explored with SoMe research include understanding attitudes towards vaccines, depression among college students, recovery from anorexia, and virtual concierge medical clinics (8, 9, 10, 11).

Given the increasing interest in SoMe research, attention to the field of research ethics is important. In the last century, research studies that resulted in human suffering and death shaped our current federal regulations and codes of ethics governing human subjects research. These events ended with the Belmont Report which indoctrinated three main principles that still remain at the cornerstone of human subjects research ethics (a.k.a. “The Common Rule): respect for persons, justice and beneficence (12). In 2015, the Department of Health and Human Services (HHS) announced proposed changes, also known as “Notice of Proposed Rulemaking” or NPRM, to the Common Rule for the first time since 1981 (13). While the NPRM expresses a need to re-evaluate the Common Rule in the context of new research settings and practices, there is no specific mention in the proposal of SoMe and the unique risks it presents when used for research purposes (14).

The Food and Drug Administration (FDA) and HHS have separate, but somewhat similar or complimentary; codes of federal regulations based on the Common rule and proposed rules once enacted. To ensure these regulations are followed, every institution that receives federal funding has or hires an external research ethics committee known as an institutional review board or “IRB”. IRBs exercise the power to approve or disapprove researchers’ requests to begin studies or make changes to one in progress. IBRs base their decision to approve or disapprove researchers’’ request by performing a risk analysis of each study, balancing the need to protect participants’ rights with the benefits the study promises to society at large. When IRBs need more guidance to perform a risk analysis than what is offered in the current regulations, they turn to federal guidance issued by the FDA or the Office of Human Research Protections (OHRP) within HHS. IRB professionals currently review SoMe research without either regulations or guidance to refer to. Establishing new guidance or regulation takes months, if not years, and clashes with the full-speed-ahead culture of emerging technology like SoMe. In the meantime, different IRBs will continue to deny approval of studies wishing to incorporate

SoMe using without universal criteria that permits consistent justification of IRBs' determinations.

This lack of universal criteria for IRB review of SoMe research increases the chance that IRB professionals' will miss or minimize ethical risks. IRBs' authority and competence surrounding SoMe research was called into question when Cornell University's IRB failed to provide proper oversight to the Emotional Contagion Experiment. The ethics of SoMe research hit the news again weeks ago when academic researchers in Denmark posted cross-national data from approximately 70,000 OK Cupid member profiles without IRB review (21, 22). These news stories alter the public's perception and that of researchers themselves. If SoMe users doubt the solidity of IRB professionals' competency, they could be less likely to participate in such research in the future. This same influence could deter researchers from engaging in SoMe research, thus hindering the innovation attained when capitalizing on technological advances.

Many groups are working to address the shortcomings of our current regulations related to social media. The Secretary's Advisory Committee on Human Research Protections (SACHRP) advises HHS in ways that may shape the department's decisions to change their regulations. SACHRP offered recommendations on internet research in 2013, acknowledging how shifting technology challenges the existing ethical framework (15). Further, the committee presented the possibility that sensitive data is more commonly collected via SoMe. The recommendations explained how data was "logged" by SoMe, necessitating an understanding of SoMe data's life cycle for improved regulation (15). SACHRP went on to consider "identifiable data" in the report without regard for the ways that SoMe research challenges this definition. These ways include geotagging and attaching IP addressed to SoMe data, often without either the participant's or the researcher's knowledge and approval (15). Additional guidelines specific to research ethics and SoMe have been offered by professional associations and organizations including the Association of Internet Research, the American College of Physicians, and the Federation of State Medical Boards (17, 18). The National Institute of Mental Health has also taken space in this arena by establishing a workgroup that "review the opportunities and challenges of using new information technologies to study human behaviours" (19).

Even with all these efforts being made to establish SoMe research ethics, interested parties struggle due to a lack of definitions. The federal regulations define "research" and "human subjects" but their interpretation are muddled once applied to certain situations. For example, some social computing researchers passively collects data from SoMe profiles they consider publicly available (20). The difficulty of establishing SoMe research ethics is further confounded when searching for definitions of "social media". As the number of platforms, applications, uses, and tools increase, so does our dissatisfaction with definitions that fail to encapsulate them.

Previous research has been gathered on the perspectives that adolescent SoMe users, Amazon Mechanical Turk workers, researchers, and academics hold towards the ethics of SoMe use in general and for the purpose of research (23, 24, 25, 26). In one study with 132 adolescents at a state university, participants had Facebook profiles that were publicly viewable. The research team reviewed these profiles and then disclosed this information to profile owners, asking for their response to this sampling method. Overall, participants viewed the method positively with 19.7% endorsing it and 36.4% deeming it fine. Only 9.1% were uneasy with the sampling method. Privacy concerns were communicated more by participants who were neutral or uneasy with this method when compared to participants who endorsed it or said they were fine (23).

In another study of 3,509 Amazon Mechanical Turk workers, participants were presented with five experimental scenarios and were asked to share their level of disapproval and concern for each. One of the five scenarios described the Facebook Emotional Contagion study (commonly referred to as "The Facebook Study") where the emotional content of Facebook users' newsfeeds was manipulated by reducing positive expressions in their newsfeeds and observing users sharing less positive posts and more negative posts. When negative expressions were reduced, the opposite (more positive posts and less negative posts) was observed (21, 24). Ten variations of the study were presented and included one exact description of the study, a variation where it was stated that the study results would be published, and a variation where the results of the study would be used for product development. None of the variations of the original Facebook Study produced significant changes in rates of concern or disapproval. Compared to non-SoMe scenarios (i.e. phishing and spamming), the Facebook Study elicited the most concern and disapproval only when participants were not already familiar with the study. When participants had heard about the Facebook Study, they expressed more concern and disapproval for scenarios that involved phishing and spam (24).

Online data researchers (n=263) were surveyed about their personal code of ethics when conducting research. Responses to open-ended questions revealed that protecting individuals, informed consent, and balancing risk to human subjects were the most commonly held values, respective in order of participants endorsing the value. Differences in responses were not correlated with professional discipline, methodological approaches used or workplace affiliation. For ethical guidance, participants referred to the Belmont Report, Common Rule, IRBs, websites' terms of service, the Hippocratic Oath and the Golden Rule.

Less than one quarter (22%) of study participants believed consent to always be necessary when collecting data online. Approximately one third (30.5%) of participants shared research results with participants in their own study and 56.9% believed that online data should not be collected if the risks of conducting the study outweighed the benefits (25). Researchers in Mayalasia and Britain teamed up to host an online survey with 30 responses from academic staff members at one international university with sites in different countries. Questions focused on attitudes towards social media research ethics (SMRE), familiarity with and training on SMRE guidance, and experience reviewing the ethics of proposed research from students and researchers on social media.

A 12-item survey called the “Attitudes Towards Social Media Research Ethics” survey was formed and tested for reliability with item-total correlations from r=.465 to r=.804. After removing two questions from the survey that had little to know association with the remaining ten questions, Cronbach’s Alpha=.889. Overall scores on the survey were not associated with level of experience reviewing SoMe research or level of training and familiarity with SMRE guidance. Findings revealed high variance in academic attitudes concerning SMRE.

While many participants agreed that researchers should try to avoid deception whenever possible and gain consent from participants before doing SoMe research they also shared an awareness for the difficulties often faced trying to do so. There was a lack of congruence when participants reflected on their confidence level if deciding to release SoMe data. This discrepancy in confidence level was attributed to the skepticism some participants felt when considering their ability to de-identify the SoMe data. A more balanced response was demonstrated when participants were asked if it would be acceptable to collect SoMe data without informed consent (43.4% disagreed; 56.6% agreed) (26).

This previous research adds to our existing knowledge of SoMe research ethics, no research has been done with IRB professionals to capture their opinions about SoMe in general and SoMe research familiarity using SoMe, or their recommendations for improving the current system of SoMe research review. This improvement will require the involvement of multiple sectors, including government agencies, SoMe companies and academia. Saving a place at the table for IRBs can produce more feasible solutions to the presenting problem: an absence of formal direction or support to keep IRBs informed enough to review studies that use SoMe and guide researchers on this issue. The present study had four goals. The first was to understand IRB professionals' attitudes and beliefs regarding SoMe in general and in research. Second, this study explored what particular risks were identified by participants, caused the most concern and reasons for expressed concern. Third, the study assessed participants' use and familiarity with SoMe technology. The fourth goal was to gather recommendations participants offered for the regulation and ethical review of studies using SoMe.

Methods

The rationale for the design of this qualitative, exploratory study was to allow IRB and ethic professionals' ample time and freedom to share their beliefs, opinions and attitudes on the ethical use of SoMe. To do this, a grounded theory methodology was employed, using an interpretivist method where the researcher does not form expectations of the study outcomes before data collection (27). The University of Washington IRB reviewed our study protocol and determined our study was exempt.

Subjects

Eligibility criteria included being between age 18 and 99 with a previous work history of reviewing the ethical conduct of human subjects research in the U.S. for a minimum of six months. All subjects had to also be fluent in English. Thirty IRB's were chosen across the country from academic institutions, medical facilities, private institutions, and government agencies. It was important to select institutions all over the U.S. because focusing only on local institutions would threaten the confidentiality of subjects since the IRB community in the Seattle area is fairly small. Type of institution was not limited to one kind (e.g. academic only vs. medical only).

Recruitment

We identified subjects for this study using convenience sampling which is based on availability for participation and availability of contact information. We combined convenience sampling with snowball sampling by asking each subject for the names and contact information of other people that would most likely be eligible for our study (27). Using a combination of Google searches, LinkedIn private messaging, LinkedIn groups and referrals from other subjects, we called, emailed or sent a private message inviting them to participate in a study about ethics and social media. Contact attempts were made to the phone number and email listed on the IRB website whenever possible.

Since IRB staff members are rarely involved in studies as subjects, we recorded all contact attempts and referral sources in real time in order to see how responsive this community would be. In addition, collecting this information can reduce the burden placed on the subject by ensuring that all contact attempts are done with the consideration of best times to reach subjects and track preferences for phone calls that include preferred name or contact method.

Data collection

The first set of questions was close-ended questions to capture demographic information. There were additional close-ended questions asked to better understand if participants wanted to see changes made at the regulatory or organization level concerning the use of SoMe for research purposes. Additional close-ended questions asked about participants' use of SoMe and work experience specific to the review of SoMe studies. Open-ended questions followed and covered these same topics plus questions about participants' attitudes and beliefs related to SoMe. Social media was defined as "websites that provide opportunities for user participation in the creation and display of multimedia data". Examples included Facebook, Twitter, Google Plus, You Tube and LinkedIn. When participants had broader definitions of social media, they were encouraged to share these and use the definition they thought best described "social media". Some participants offered definitions that were more inclusive of applications and devices. Participants were told that they should consider any use of SoMe for research purposes including recruitment, locating, follow-up, content analysis, observation and intervention. The term "social media research" was referred to for the rest of the interview to encapsulate all utilization for research purposes.

Interviews

Interviews were one-on-one with a trained graduate student who was also a former IRB reviewer. She informed all respondents of her previous work experience during the recruitment phase in order to gain interest in participating and credibility. She then explained the study and obtained verbal consent. Interviews took anywhere from 30 minutes to 2 hours to complete and were audio recorded. All subjects were provided with a $10 incentive after completing the interview. A transcription service was hired to transcribe the data verbatim.

Analysis

Analysis of close-ended questions was limited to reporting of number of participants per response option and percent of total sample. Open-ended questions were coded based on grounded theory methodology to perform ongoing content analysis during data collection (27). A codebook was set up to enter data from both types of questions. For open-ended question responses, the codebook was built using an inductive approach, meaning codes were only selected after data collection. Coding began upon completion of the first interview and started with tag coding which entails entering direct quotes from the data into the spreadsheet. Two rounds of tag coding took place before some of these codes were then recoded. Some were assigned ordinal values to create scales (e.g. never, once in a while, sometimes, frequently, all the time).Other tagged codes were recoded as categorical variables (e.g. the personality profile of the responding participant is that of an innovator, a regulator or both). Interval coding also took place after tag coding which involved counting the number of times the code appeared in the data (e.g. number of times participants said something about privacy risks (28).

During the coding process, memos were created to identify and describe connections that arose between codes and later formed themes. Memos were also used to capture the research team's ideas and to track qualities about the data, like when responses from the same interview conflicted with one another. All codes were then summarized as themes and areas for future research. All themes were discussed by the first two authors and illustrative quotations were selected for each theme.

Coding took place in four waves using a comparative method of double coding. Double coding was done to increase the likelihood that codes, and eventual themes, accurately reflected the participants' responses. In wave one, the principal investigator (T.W.) coded five of the transcribed interviews. The second investigator (M.M.) then coded the same interviews and any discrepancies in coding were discussed and recoded when necessary. In wave two, another five interviews were coded by these two investigators and discrepancies were addressed. Another sixteen interviews were coded by the principal investigator in wave three. Discrepancies were identified and recoded when necessary. The resulting codes were organized into themes that were then collapsed into over-arching concepts.

Results

Participants

A total of 31 participants completed the interview (91% response rate) with one interview being lost due to technical difficulties during audio recording. The majority of participants were age 31-50 (58%). Our sample included 17 female participants (57%); and white (n=27; 90%). Approximately one quarter of participants lived in the northeast and another quarter in the northwest. The professional role of each participant was categorized into nine categories that included Bioethicist, IRB Administrator, and IRB Board Member. Most categories had no more than three participants but the most commonly held role (n=8) was IRB chair (Table 1).

Experience and Frequency Reviewing Studies Using SoMe

Most participants had reviewed studies proposing the use of SoMe (Table 2) and shared a wide array of ways that they had seen researchers using SoMe. These included the use of Facebook ads, Facebook groups, contact information after losing participants during follow-up, tweets used in classroom settings, artists in a brand community called Behance, content analysis of tweets during the Ferguson riots, and downloading big data sets of hashtags and screenshots. Seventy-three percent said they thought the overall use of SoMe in research was increasing with their own IRB receiving less than 5% (n=9) or less than 25% (n=10) (Table 2). The majority of the sample also used SoMe for personal reasons and professional reasons (Table 2). Overall, participants' views, experiences, attitudes and recommendations regarding social media, both in general and specific to research ethics, were varied across themes.

Federal Regulations vs. Federal Guidance

When asked if participants would like to see new federal regulations or federal guidance on the ethical use of SoMe in research studies, guidance was often supported (n=23; 77%) while regulations were not (n=4; 13%). Participant comments in this category included statements that regulations took too long to be written, let alone approved, to remain relevant when applied to ever-changing SoMe technology:

> *"I'd probably prefer guidance, because it's more likely to happen. Also, it gives people wiggle room to deviate when they feel like the circumstance merits."*

Themes

The researchers identified three themes common to participants when responding to open-ended questions. These themes were: 1) assumptions about potential ethical risks when using SoMe in research studies; 2) responsibility of keeping SoMe users informed of these risks; and 3) framing of privacy risks within the context of SoMe settings.

Theme #1: Participants conveyed many assumptions about how much they know in terms of ethical risks with social media research. Risks they identified varied by number and kind.

Transcripts were coded for any risks, either to SoMe users or researchers involved in SoMe research, which were discussed during the thirty study interviews. During these interviews, some participants had a hard time conceptualizing an issue enough to answer the question or hastily answered the question without taking any time to really process what the question was asking. In those cases, scenarios based on real-life situations that typified the ethical conundrum of interest were presented to elicit additional consideration.

One example came from the principal investigator's (PI) personal experience and was presented to participants when they quickly stated that all publicly available data on SoMe is fair game because the SoMe user chose to make it so. The scenario described how the PI had privacy settings for their personal Facebook account set to limit viewing of their photos to only their Facebook friends. Unfortunately the PI did not realize that the default privacy settings on their smartphone's Facebook application were not automatically set to mimic the settings they chose for their Facebook account using their website. As a result, they had uploaded photos to their personal Facebook account from their phone, assuming they were only viewable by their friends when in fact they were accessible to the public.

Twenty different risks were identified and coded for, ranging from concern about IRB professionals' preparedness to review SoMe research to concern of harm to the greater community of interest in SoMe research. These risks are listed in Table 3 by order of highest number of participants mentioned the risk to lowest number of participants mentioning the risk. They were then grouped to form theme #1. This theme was selected because of how frequently, overall, the identified risks were mentioned during interviews. An equally important reason for shedding light on this theme was the research team's understanding of the core function of an IRB and its members when reviewing human subjects research, including SoMe studies. If IRB professionals are unable to identify ethical risks, they could easily overlook potential for harm to study participants during their review of new or ongoing research. To illustrate the wide scope of themes identified, we will now present the five risks most commonly mentioned during our interviews.

IRBs Unprepared to Review SoMe Research

Most respondents, 20 of the total (67%), identified the risk that IRB's lack sufficient readiness to perform a thorough and accurate risk analysis during their review of SoMe research. Reasons for this concern were one of five categories:

1) IRBs are too busy staying informed with other topics that come up more often in their reviews.

2) SoMe technology is evolving too quickly for IRBs to stay fully informed of potential risks.

3) IRBs are unsure how to assess ethical risks presented with the use of SoMe due to a lack or federal regulations and/or federal guidance on this issue.

4) IRB professionals choose to not understand SoMe because they either undervalue the relevance that SoMe technology has to research or just dislike the idea of it being used for research purposes.

5) IRB’s are unsure of the SoMe user experience so they over-regulate, thus stalling innovative research.

Participant responses in this risk type included comments that they were accepting of the method used for this study, but did not convey enthusiasm about the use of SoMe research in general. Examples of individual participants’ responses included:

> *“Long as study teams can tell prospective subjects, ‘We’re going to track you on Facebook.’ and the prospective respondent is a competent willing adult…then the IRB ought to give precedence to that autonomous agent’s decision to take part in that research even given our misgivings about social media as a way to conduct research. That’s important.”*

> *“There really is no exemption category for the kind of research that most of us do with social media. IRBs have for 20 plus years classified these as standardized tests and surveys even if that's not really what they are. Even if it's a survey where you ask people to do things rather than just answer questions because they know that the work is in concept exempt but the regulations don't get updated to create new categories.”*

> *“ I think the IRBs that (the unenlightened ones) just require everything to go through full judgments which is a waste of everybody's time, …they are afraid*

> *of the liability that would come up if something slipped through under the auspices of some sort of a rule or guideline that shouldn't have."*

Privacy Expectations

The privacy expectations that one holds when using SoMe was another commonly identified risk (n=20; 67%). When discussing the difficulty of determining public space from private, many participants felt that the expectations one has in different settings should weigh more than a concrete definition of "public space". Such a definition cannot be flexibly applied to address all the nuances presented in SoMe environments:

> *"In each of these different settings we go in with different expectations and social media is still so wide open that I don't think that anyone on a rational basis can say, 'We expect our transactions and our presence on social media to be private,' unless we make it so."*
>
> *"I think users have different expectations for what's private in Facebook than what they do in Twitter. People's behaviors on Facebook and Twitter are different."*

There was also concern that IRBs assumed people using SoMe had higher expectations for privacy than they really do:

> *"In my mind, I know that ... make the assumption that most people are going to operate with their safeguards in mind, whereas the older generation may not necessarily know that that's the conduct that you engage in online, will believe that the threat is bigger than it is, and will not intuitively and instinctually ... their threat analysis is different"*

Some felt that privacy expectations should be only one aspect of what is considered when determining parameters that researchers can operate in and still respect one's privacy:

> *"...reassure certain sites that okay, these are the parameters. ...They would now feel a certain sense of reassurance themselves that I can post this with the same degree of comfort that I can post this on my company's website, and know that what I've put there will stay exactly what it is. If I need to change it, it's within the field of my control to change it and this is what it will look like."*

Participants pointed out that the reasons we use SoMe technology is changing and now can include financial transactions and health data. The kind of information on SoMe could also dictate the level of privacy expectations that both the SoMe user holds and the IRB should consider:

> *"Like on a playground or in a classroom we have control over who we want to share with and who we want to connect with. That's different than in these other settings where there's tight control over the sharing of medical of financial information and the expectation that it is going to be kept private and that it's not going to be further shared unless I authorize it. In each of these different settings we go in with different expectations and social media is still so wide open that I don't think that anyone on a rational basis can say, 'We expect our transactions and our presence on social media to be private' unless we make it so."*

User Agreements

Overall, 17 participants (57%) specifically commented on the user agreements that all SoMe users must agree to in order to use this technology. One main concern within this identified risk was that no one, participant or researcher, reads or understands them. Examples of participants' responses included:

> *" the social media accounts are set up in a way that the user is not necessarily aware, so I think it's a 2-pronged issue where Facebook, Twitter, et cetera needs to better illustrate to the user what can be done and how it can be done. Ideally, nobody is going to read a 40-page long terms of agreement".*

The other main concern expressed was that user agreements change all the time with social media companies adequately informing users of these changes:

> *"We have to make them aware at the time we solicit their consent or permission to take part in research with … during the course of this study …please be aware that unbeknownst to you, your privacy settings may be changed by updating or agreeing to terms of condition of participation".*

Consent

Sixteen (53%) participants brought up the risk of consent during their interviews. Within this topic, concerns included the difficulty of gaining consent via SoMe technology:

> *“Because as you know the Facebook study that generated so much controversy. They supposedly had a little bit consent in terms of their user agreement. But that did not meet the Federal standards of consent, so what is acceptable in that environment?”*

Assumptions that consent is not required to collect or use SoMe data were held by the participants themselves or expressed as a concern for other IRB professionals and researchers:

> *"Do you have any special ethical obligation when … the content…is public? We've come to a general conclusion that the only time we feel a special obligation around privacy of data that's been made public is when we're dealing with one of three cases, when we're dealing with children, when we're dealing with vulnerable populations and when we're dealing with information that was made public about a third party who did not consent.”.*

Last was the difference in how participants consent to research on SoMe compared to other settings:

> *“You don't really have to worry about whether clicking a button or check box is sufficient consent.”*

> *“That’s what we should expect from the study teams and IRBs, is that they’re going to be transparent and sufficient enough to give social media participants the opportunity to say, ‘Hey, it’s not the open setting I know it to be because there are people here who are not participants. They’re observers or researchers and their motives are different from all my other contacts”.*

Defining Public Space and Public Information

Half of all participants (n=15) mentioned the risk of researchers, participants and IRB professionals being unclear about how to determine which spaces and what information is public. Many shared their frustration that there is no definition of the term “public” within the code of federal regulations, leaving individuals unsure what criteria to use when determining how public or private settings and data are. This determination of space and type of information played a central role when determining whether or not the study should require consent and what kind of IRB review would be warranted (e.g. exempt, expedited or full):

> *"If information is available online and is publicly accessible, for the most part it is not considered confidential. However, there should …limitations placed on what information can be used." For some, a definition of public vs. private is not enough: I think there's still some room for a case by case evaluation. Just because you posted something ten years ago on a forum that at that point was private, and has been bought by another company and has made all those things public…there's still a point at which the researcher has to really think about the true original intent."*

Theme #2: Participants also expressed varied ideas and assumptions about 1) whether or not SoMe users *can* accept responsibility for staying informed of the risks described in theme #1 and 2) who *should* be responsible for SoMe users informed of these risks once research is introduced into the SoMe environment.

This theme built off of theme #1 and was comprised from comments made by the study participants about how knowledgeable SoMe users should be when it comes to making decisions about their behavior on SoMe. The behavior included specifically when SoMe users knowingly and unknowingly agreed to participate in SoMe research. Unknowingly agreeing to participate in SoMe research described the scenario of researchers extracting data from SoMe users' profiles without informing them first or asking for their consent because they deemed the data 'publicly available'. Here we will provide results about SoMe users' acceptance of responsibility first and then follow with results about who should be responsible for keeping them informed during SoMe studies.

Can SoMe Users Accept Responsibility for Staying Informed of the Risks Described in Theme #1?

Some participants felt that users who agree to the terms of service in order to use SoMe also bear the responsibility of keeping themselves informed. They can , and should be expected to know, that everything on SoMe is public:

> *"If somebody wants to post stuff about themselves ethically we've decided we don't have any qualms in using that content because it's already public and legally we're pretty clear it doesn't need any protected information guidelines"*.

Others disagreed with this perspective and assumed that most SoMe users, regardless if they can or not, should not accept responsibility for staying informed of the risks they may incur if participating in a study with SoMe:

> *"But I think philosophically, I don't like that whole well everything's public, I have nothing to hide, you shouldn't worry. I think that starts to really erode on a very human need for privacy."*

For those who felt SoMe users are able to accept the responsibility of identifying the risks they may incur in SoMe research, some participants in this study assumed they would not be willing to. This assumption based on another underlying assumption that SoMe users' value convenience and immediacy of use over taking the time to understand the risks they may incur:

> *"Yeah, you want access. Yeah, yeah, yeah. Just submit or agree and get it out of my way so that I can participate."*

When participants doubted SoMe users' ability to be informed of these risks, the interview shifted from a focus on SoMe users' ability to who the participants thought should be responsible for keeping them informed during studies using SoMe.

Who Should be Responsible for SoMe Users Informed of These Risks Once Research is Introduced into the SoMe Environment**?**

This dilemma came up quite a bit in interviews, with participants oscillating between the IRB, the researcher, the SoMe company, the participant and several combinations of these different parties. For many participants in this study, the burden clearly laid with the researcher:

> *"…my general thinking is the investigator has a considerable responsibility when it comes to this. Because they're interacting with the human subjects."*
>
> *"We're not imposing those terms. It's really important for researchers to remind their participants, their subjects that look, I'm not, you have your own account here. You are subject to those terms of service."*
>
> *"From a researcher perspective, I worry (about that) we as researchers are relying on third party sites as the basis, whether it's Facebook or whether we're using Twitter or whatever. We are really not completely in control of the research because we are forced to operate according to these legal standards of their terms of service or their end user license agreement. I worry … that we may truly, truly think that the work we're doing is without any risk or without any possibility of harm but a lot of us don't really know what is going on behind the scenes in terms of data processing, in terms of algorithmic manipulation, in terms of how much data is bought and sold every second."*

For others, the IRBs had a role to play in this responsibility but they could not fulfill this duty without the help of other offices external to the IRB but within the same institution:

> *"…the IRB, I don't think that it's really our scope to understand every nuance in a very legalistic document. That's where we do have to rely on our colleagues and our legal offices and then our IT* people."

Yet some deemed the responsibility evenly shared between the IRB and the researchers:

> *"…then the responsibility for both the boards and the investigators is that these prospective subjects have the expectations of privacy and confidentiality that shall not be violated."*

Few put the responsibility on the SoMe users because participants did not expect that they would receive notification that they were in SoMe research by accessible and transparent means. None of the participants mentioned SoMe companies' obligation to informing SoMe users of possible risks should they participate in a study using their SoMe data.

Theme #3: When participants were asked to identify risks they associate with SoMe research, 90% were privacy risks. Framing of privacy risks within the context of SoMe settings was further described in participants' responses.

Building off of themes 1 and 2, privacy risks rose to the top level of concerns that participants communicated when analyzing the risks of SoMe research. The importance of privacy seemed to be intimately interwoven with thoughts about SoMe users' privacy expectations:

> *"If people willingly and knowingly post something publicly, then I think it's fair game that they put it there."*

As seen from responses to the questions asked of all participants, SoMe users' obligation to keep themselves informed of the limits to privacy was just as intermingled as privacy expectations:

> *"If it is out there in public online, how confidential is it?" To which a typical response was: "It's not confidential at all. If the person put it out there themselves". Privacy settings shared this space with the topics of privacy expectations and obligation of users to stay informed: "Check your privacy settings. Don't post anything that you wouldn't want to be public…It's kind of unfair they didn't realize. Especially in a scenario like you just gave where …even if you'd set your privacy settings in a certain way the actual device would sort of trip you up."*

Many tried to put the uncertainty of privacy and SoMe in context of other factors better understood on this issue:

> *"…the privacy issues related to social media research are different in nature than perhaps other types of studies in that one, unlike say … our medical records or our credit card records or our educational records, these are records the use of which has been well established. The use of research for which also has a long history. This cannot be said of social media activities… certainly compared to the*

> *other records and interactions, a relatively new preoccupation, the parameters of which in terms of privacy and confidentiality are not well established."*
>
> *"It's like being on a playground or in a coffee house or in a conference call. What we say will be and what we do, will be seen or overheard by others and we enter into those settings willingly. If we sign up for Facebook, if we use Instagram, if we use LinkedIn we use these media knowing full well that they are communal, largely communal settings with untold amount of members of the community."*
>
> *"It's unlike being in a doctor's office or applying for a credit card or applying for social service benefits. We have an expectation in those settings where the information we divulge will be kept private and not shared and the laws are crafted to do just that…That is not our understanding when we go into social media. There are no such laws. We go into it, we should go into it eyes wide open. What we post is going to be seen."*

Framing privacy in the context of SoMe research also involved regard for the researcher's intended use of that data:

> *"Observations of public behavior are not research. You can do observations of public behavior, and you don't have to go through IRB approval and all that. You might just have to submit an exemption type form or something."*

Minor Themes:

While the complete description of all themes and their construction cannot be described in one paper, it is important to note that the analysis of this data brought forth a wide variety. Themes that were only mentioned by five or less participants included encryption, permanence of posted content, inability to control sharing and comments, reporting of self-harm or criminal behavior, social media companies selling data to third parties, HIPAA compliance, geotracking and harm to third parties and the greater community.

Encryption was only mentioned by five (17%) of study participants:

> *"The encryption, the transmission, accessing it. Researchers and IRBs are attuned to those requirements. We're pretty much on the same page as to what we ought to be looking at in terms of data security, confidentiality and privacy. We know that the issue's out there. It's whether what we say we'll do or how we'll consent subjects or how we'll keep the data secure. That may differ, but we know*

> *that the requirements are there. It's how they're operationalized that may be different, ... but they'll know that that is an issue and it has to be addressed as opposed to say the respondents or the social network participants who aren't aware of these issues.]"*

The same number of study participants also brought up the issue of data permanency once posted, comment on or shared within SoMe settings:

> *"It's going to be permanent unlike a conversation in a hallway or an activity in a playground, social media interactions are in a way recorded, as a Facebook study demonstrated. People's conversations, their reactions, their likes or dislikes. They have a permanency that other social networking environments do not have because the data are captured. There's a lot of interest in capturing and then using that data unlike those other settings. Because of those other considerations implicated by social media networks both IRBs and certainly researchers should be aware of these things."*

Data permanency was also related to the research team's obligation to report certain disclosures, include criminal activity, to government authorities like law enforcement:

> *"when they post they have no control, and that would be something that, when you're looking at enforcement, if they have posted it in the way that it's been approved, and it's been subsequently reposted, then there needs to be a clear line of what are they responsible for, if it's been reposted and it's been changed."*

In terms of HIPAA compliance, it was agreed by different participants that our standards for privacy and confidentiality are often influenced by HIPAA guidelines but do not necessarily fit well with the way privacy and confidentiality are shaped in SoMe environments:

> *"We're asking them questions about privacy and confidentiality that are framed in HIPAA terms right, and clinical research terms, but not in social media terms. I would hope that the regulations allowed us, as an IRB to ask different types of questions and more relevant questions too for students and researchers."*
>
> *"This comes up in Twitter a lot, IRBs tend to be very conservative about using Facebook and Twitter because we're used to HIPAA models of privacy. I would be ... I'm less conservative. I would permit more I think, than what a lot of IRBs do."*

Discussion

The present study sought to understand IRB and ethics professionals' attitudes towards SoMe and familiarity using the technology. It also aimed to identify ethical risks associated with SoMe and recommendations that IRB and ethics professionals' offered for the regulation and review of this research. Three major themes arose from the data: 1) assumptions about potential ethical risks when using SoMe in research studies; 2) responsibility of keeping SoMe users informed of these risks; and 3) framing of privacy risks within the context of SoMe settings.

In the first theme, more than half of the participants questioned IRBs' current readiness to accurately analyse studies using SoMe for ethical risks. Reasons for this concern included the workload of IRB professionals limiting time for continued education. The evolving nature of SoMe technology compounded this concern. Over-regulation was offered by some as a reaction that IRB professionals had when feeling ill-informed about how SoMe actually works. In the context of SoMe research, participants either felt confident or unsure when determining IRBs' understanding of privacy expectations, user agreements, consent, and determination of public vs. private space and information.

Many participants hastily determined that all SoMe profiles and/or data was publicly available and therefore did not require IRB review. Scenarios were offered to participants who jumped to this conclusion. Most of these participants expressed surprise when realizing that there were key factors they missed or were completely unaware of when making this determination. As a result, many participants who were not in favour of IRB professionals receiving additional training or institutional policies on the ethics of SoMe research changed their mind. This supported the idea proposed by others who conduct research on ethics: presenting scenarios of ethical conundrum can lead to valuable insights and training on SoMe research ethics (24, 29).

In the second theme, diversity was again found when IRB and ethics professionals considered how well SoMe users identified potential risks when considering participation in studies using SoMe. Some participants assumed that most SoMe users were very well-informed, by the very nature of their ability to use SoMe technology. Others assumed that SoMe users were unconcerned about these risks because prioritization of immediacy and convenience in SoMe environments overshadowed the risks they may incur. During this discussion, participants also wrestled with the question of responsibility to keep SoMe users participating in SoMe research informed of these risks throughout the study duration. Some placed this responsibility with the user themselves while others looked to the researcher or IRB. Interestingly enough, no one placed responsibility with SoMe companies. Reflecting on these responses, assumptions were definitely made that could be challenged. The mere act of owning an online account does not guarantee that SoMe users understand privacy implications. Many users began engaging with SoMe before it was used for human subjects research; therefore feeling a false sense of security about the information they share.

Themes 1 and 2 prompted theme 3: privacy as framed specific to SoMe and SoMe research. The topics of public vs. private and privacy settings naturally arose as central to shaping one's idea of privacy on SoMe. A considerate proportion of these IRB and ethics professionals hesitated to define "public" as anything less than everything. They reasoned that SoMe users had control over their privacy settings. This demonstrated their lack of knowledge about the veiled privacy settings which default to sharing content outside one's friend/connection list and change without forewarning SoMe users. Others admitted they thought more work remains before we can envision what privacy looks like in this digital era. Others tried to liken SoMe data to health or financial records but often retracted this analogy as they thought about it longer. Intention also mattered. If the SoMe user's original intent for posting data conflicted with the study's intention, then participants' felt IRBs should step in to ensure the user's rights, both as a SoMe user and as a research participant, were not compromised.

Since there are no other studies with IRB or ethics professionals on this topic, the results of this study cannot be compared to others. However, the findings can be compared with the current federal regulations. Looking specifically at the HHS Code of Federal Regulations (CFR), Title 45 Part 46 subpart A, we see that studies are exempt from IRB approval if (30):

> *"involving the use of…survey procedures, interview procedures or observation of public behavior"*

As discussed by participants during interviews, there is no definition in the regulations of what is meant by "public". Are discussions in closed Facebook groups public if a researcher is accepted into the group but does not disclose who their intentions? Is a comment that a researcher can view on a personal SoMe home page public if the origin of that shared comment is unknown? The regulations go on to say that the exemption of IRB approval does not apply if (30):

> "*information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects"*

Among this study's results were several voiced concerns that our current definition of what we know as identifiable information (e.g. name, zip code, or date of birth) may not capture identifying information that is attached to unidentifiable or de-identified data researchers collect off SoMe, including IP addresses. In section 46.116 of CFR 45, titled "General Requirements for Informed Consent", researchers can obtain a waiver of partial or full consent if the research is minimal risk, the waiver will not harm the study participants, the study could not be "practicably" carried out otherwise, and the subjects would be informed after the data is collected when possible (30). Participants in this study shared many examples of SoMe research being done with a waiver of consent because they IRBs deemed such research low risk and impossible to conduct with consent, How can we be sure we know what the risks are to human subjects when researchers are taking data from their SoMe accounts that have not been verified as original to that SoMe user? What was the original intent of posting the content of interest? Many young adults and minors have active social lives within SoMe environments where issues of suicidality and bullying are discussed, as referred to during this study's interviews. Can an IRB assure that taking information from someone's account without their consent poses minimal risk? Should we redefine what is minimal when considering more than twenty ethical risks identified by the participants in this study? Clearly the current regulations leave us with more questions than answers when applying them to the many ways that SoMe data is being used for research purposes.

Analysis of case studies, both hypothetical and real, show up in the literature but have limited reach (24, 29). In the study by Schechter and Bravo-Lillo with Amazon's Mechanical Turk workers that was introduced earlier, the workers do not necessarily represent the typical SoMe user since Mechanical Turk is not a social networking site but instead a location to earn money in return for completing academic and non-academic surveys. The ethical scenarios presented to these workers were not limited to SoMe and only presented variations of the Facebook Study with one scenario swapping the word "Twitter" for "Facebook" (24). In another article, the authors give their personal opinions and interpretations of what risks they are concerned about when considering the different ways that SoMe research is carried out. In general, the authors raise concerns about collecting Facebook data that include consent, scientific merit and confidentiality. Diving deeper into these concerns, the authors wonder if the publicly available nature of Facebook data should outweigh the ethical importance of the SoMe user's original intent when posting or sharing such data. The commercial use of SoMe data, made possible by the terms of service agreements rarely read, was also a point of interest to the authors. The short consideration of two ethical conundrums specific to SoMe that this article provided also falls short of accomplishing the aims of this study. The discussion was interesting but failed to include the perspective of IRB professionals or any recommendations for how to improve current regulations and the IRB review process to address SoMe research's ethical challenges (29).

Implications

This study offered several implications that would help fulfill IRBs' gap of knowledge on ethics and SoMe. With enough interest in this research, the public could apply pressure on federal agencies to update the existing regulations or guidance. Our research may open the door for IRBs to re-evaluate contents of their consent form template issued by all IRBs. Regardless of institution, the current structure of most consent forms includes the rights of the participant and possible risks they face during the study. Raising awareness about SoMe and research could result in changes to template consent language, for added relevance to SoMe studies. Continued disapproval of SoMe user agreements, required for the use of most SoMe platforms, could be reduced in length and increased in transparency. Last, new training on SoMe ethics could be delivered to IRBs and researchers to prevent future IRB mishaps and promote inclusion of innovative technology in further scientific study. These changes may afford researchers interested in SoMe with more funding opportunities, publications and changes in IRB and academic hiring practices.

Limitations

The purpose of qualitative research is to highlight themes and connect concepts into a framework, not to offer generalizability. As a result, this study should be interpreted without application of the findings to other populations, larger sample sizes, or different research settings. The participants who self-selected to be in this study may have differed in qualitative ways from the average IRB professional, including their familiarity using SoMe personally or professionally and their experience reviewing studies with SoMe inclusion. Level of education, geographic location, age, experience reviewing SoMe research, and professional role were not balanced well across the given sample.

Future research

Future research is needed to understand if the roles of IRB and ethics professionals, location or institution type play a role in their views and ability to assess the ethics of SoMe research. This additional study, along with exploration of new themes and concepts, could bolster this very new area of research. More qualitative data should be collected so that a conceptual model can eventually be established. This model could guide best practices for IRBs and ensure that any future change to the federal regulations or federal guidance will accommodate IRBs' needs and preferences. New studies could accumulate information about IRB professionals' opinions of SoMe companies' privacy policies, their reaction to news stories on privacy and SoMe, and their evaluation of technological innovation for debriefing participants following deception. Without continued research on IRBs and social media, ethics professionals will continue to review these studies in the dark, unnecessarily rejecting studies and overlooking potential risks. A new study is currently building an online, social network for researchers, IRBs, tech and legal experts to share ideas and tools for the design, implementation and oversight of SoMe research (31). New studies to track these nuanced ideas can present a more accurate picture for us of what the system really needs. Clearly SoMe is not going away so neither should our pursuit of the right solution for a timely and growing problem.

Acknowledgements

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Table 1. Demographic Characteristics

	Participants	
	Count	**Percent (%)**
Age		
21-30	2	7%
31-40	9	30%
41-50	9	30%
51-60	5	17%
61+	5	17%
Race		
Caucasian	27	90%
African American	1	3%
Asian	1	3%
Mixed Race	1	3%
Geographic Location		
Northeast	8	27%
Northwest	8	27%
Midwest	5	17%
Southwest	5	17%
Southeast	2	7%
Outside U.S.	1	3%
Level of Education		
Some College	1	3%
Bachelor	3	10%
Master	10	33%
Doctorate	9	30%
JD	7	23%

Table 2. Review of Studies Using SoMe

	Participants	
	Count	**Percent (%)**
Studies Reviewed		
Yes	21	70%
No	9	30%
% of Total Studies Reviewed		
Not Sure	2	7%
None	4	13%
5% or less	9	30%
25% or less	10	33%
50% or less	3	10%
75% or less	0	0%
100% or less	2	7%
Change in Number of Studies		
Missing	2	7%
Not Sure (lack of experience, not on IRB now)	4	13%
Increasing	22	73%
Decreasing	1	3%
Staying the Same	1	3%

Table 3. Risks of Using Social Media for Research Purposes as Identified by Participants

Risks	**Number of Participants**	**Percent (%) of Participants**
IRB's not informed enough to review SoMe research	20	67%
SoMe Users' Privacy Expectations	20	67%
User Agreements	17	57%
Consent	16	53%
Lack of Clarity in Discerning What is "Public" Space and/or Information	15	50%
Validity of Data	11	37%
Privacy Settings	10	33%
Deception	10	33%
Special Populations (e.g. children, cognitively impaired, suicidal)	10	33%
De-identification	8	27%
Sensitive Topics (e.g. child safety, self-harm, criminal activity)	8	27%
False Identities on SoMe	6	20%
Encryption	5	17%
Permanence of Content Posted on SoMe	5	17%
Comments and Sharing Out of Researcher's Control	4	13%
Reporting (e.g. mandated reporting, criminal activity)	4	13%
SoMe Companies Sharing Data with Third Parties	2	7%
HIPAA Compliance	2	7%
Participants' Location Unknowingly Shared	1	3%
Harm to Third Party or Greater Community	1	3%

Appendix A. Information Statement

SOCIAL MEDIA AND IRB STUDY

INFORMATION STATEMENT

Investigator’s Statement:
We are conducting a study about the beliefs and attitudes institutional review board (IRB) staff members have regarding the use of social media in research and how those thoughts and beliefs shape their review of study applications. This consent form gives you the information you need to decide whether or not to be in the study. Please read the form carefully. You may ask questions about any part of the study at anytime. When your questions have all been answered, you can decide if you want to participate. This process is called ‘informed consent’.

PURPOSE

This is a study where we will ask you a set of close-ended and open-ended questions to better understand how the use of social media for recruitment of participants, delivery of interventions, and analysis of social media content is viewed by IRB staff when reviewing study applications. The purpose of the research is to find out where those thoughts and beliefs come from and how they influence process of study review by IRBs.

PROCEDURES

Interviews
If you agree to take part, you will be interviewed by one of our research staff over the phone or in person. All interviews will be audio recorded for future content analysis. Telephone interviews will be completed at a location of your choosing that will provide privacy. Every effort will be made to schedule the interviews at a convenient time for you. Your name will not appear on the interview.

The interviews will take 20 to 30 minutes. We will ask you questions about your thoughts and beliefs regarding social media and any training or resources that you have used when reviewing research involving social media

> Here are a few examples of some of the questions you will be asked.
>
> *What are your biggest concerns about the use of social media websites (SMWs) in research? Can you provide me with examples?*
>
> *If you could provide training to other IRB reviewers on what are the most important things to look for when reviewing social media research, or research specifically using SMW’s, what would you include and why?*

You are free not to answer any questions you do not wish to answer.

Confidentiality

The interview is voluntary and strictly confidential. You do not have to answer any questions you do not want to and you can end the interview at any time. If you have questions we can answer them now or any time in the future. All data will be kept in locked storage and will be retained indefinitely. Audio files will be deleted after all interviews are successfully transcribed.

Locating Information
We will ask you for information such as your address, telephone number and/or contact information an employer to help keep us in touch with you. If you move, or if we receive additional funding for future follow-ups, we may contact you again either directly or through people who might know how to reach you. We may call you if we have a clarifying question in regards to difficult-to-hear portions of the audio recording for your interview.

RISKS, STRESS OR DISCOMFORT

Taking part in this project takes 20-30 minutes. We realize this may be inconvenient. We will schedule a time that works best for you. We will make every effort to respect your privacy. Though we cannot guarantee that your interview data will remain confidential, we want to assure you that every precaution is taken to protect you from any breach of confidentiality or invasion of privacy.

BENEFITS

You may not experience individual benefits as a participant in this study. Your responses, taken with those of others participating in the Social Media and IRB Study, may help researchers better understand the how IRB staff members understand and feel about study applications with social media. You will also benefit indirectly by knowing that you've made a contribution to research that will help other researchers and IRB staff members in the future.

OTHER INFORMATION

At the end of each interview, we will provide you with a $10 gift card in-person or will mail/email it to you as a token of appreciation for participating.

All information that you give us will be used for this research only and will be kept confidential. A code number, not your name, will be put in the computer and on the interview question response forms. All interview responses will be stored with only a code number for an indefinite period. Only researchers at the University of Washington will have access to any of your personal information or other identifying information. The results of the project will only be reported in ways that do not identify individual participants. Participation is completely voluntary and you are free to decide not to participate or end the interview at any time.

If you have questions later about the research, you can ask one of the investigators listed above. If you have questions about your rights as a research subject, you can call the Human Subjects Division at (206) 543-0098.

Appendix B. Recruitment Letter

RESPONDENT NAME},

My name is {RESEARCH STAFF} and I am a researcher (and former IRB reviewer) at the **University of Washington's School of Public Health**. We are conducting a study about the **beliefs and attitudes IRB staff members have regarding the use of social media in research** and how those thoughts and beliefs shape their review of study applications. Last, this research aims to understand what resources and materials may be referenced by IRB staff members when reviewing this research.

To be eligible for this study, you must be a current IRB staff member reviewing study applications and have 6 months or more collectively of experience reviewing studies at an IRB. If you fit these criteria, we would like to interview you. If you do not fit this description, we would greatly appreciate you recommending to us any colleagues that you think would fit this description. Feel free to call or email us with their contact information. **We hope to finish with recruitment in the next 2 weeks.**

If you are eligible and choose to participate, we will be asking you questions about your experience reviewing research with social media in the past, your feelings on this matter from an ethical standpoint, and your use of social media both personally and professionally. These measures will allow us to continue our efforts to understand how research involving social media is reviewed by IRB staff members. You are free not to answer any questions you do not wish to answer. All of the information you provide us will be kept completely confidential.

Your participation is very valuable and important to us. This visit should take between **20-30 minutes** and we will provide you with a **$10 gift card** as a token of appreciation for taking the time to talk with us. ***Would you like to do a 2 minute screening to see if you are eligible to be interviewed? If so, please call or email us at the information listed below as soon as possible.***

Thank you!

{RESEARCH STAFF NAME}
University of Washington
{PHONE NUMBER}
{EMAIL}

Appendix C. Recruitment Script for LinkedIn

{RESPONDENT NAME}

My name is {RESEARCH STAFF} and I am a researcher (and former IRB reviewer) at the UW's School of Public Health. We're recruiting participants from IRBs to learn about their beliefs and attitudes regarding the use of social media in research. Can I tell you more about how you may be able to get involved?

(If respond yes) Great! This research looks at how those thoughts and beliefs shape the review of study applications. Can we do a 2 minute screener to see if you're eligible for our study?

(If respond yes.) Wonderful! Do you speak English fluently? **(if yes)** Have you collectively worked at an IRB for at least 6 months or more?

(if yes, continue; if no, thank for time and ask for referrals to study)

You are eligible and choose to participate and your participation is very valuable and important to us. This visit should take between **20-30 minutes** and we will provide you with a **$10 gift card** as a token of appreciation for taking the time to talk with us. You are free not to answer any questions you do not wish to answer. All of the information you provide us will be kept completely confidential. Can I answer any other questions about the study before we schedule it?

When's the best time to schedule the interview with you (collect location information if going to interview in-person).

(record location, schedule time, confirm, thank)

Appendix D. Interview Question Form

Introduction: Now that we've had a chance to review the information statement and answer any questions you have about the study, it is time to begin the interview. This will take approximately 20-30 minutes. I will begin recording our interview now so please try to speak clearly and at a volume easy to hear. If at any point you need to take a break, please let me know.

Demographic:

1. **Gender**:
   a. Female
   b. Male
   c. Transgender

2. **Age**
   a. 18-20
   b. 21-29
   c. 30-40
   d. 41-50
   e. 51-60
   f. 61-65
   g. 65+

3. **Ethnicity**
   a. Caucasian
   b. Asian American
   c. African
   d. American Indian/Native Alaskan
   e. Native Hawaiian and Other Pacific Islander
   f. Hispanic and Latino
   g. Other:_________________

4. **City of residence:_____________________**

5. **City of employment: ___________________**

6. **Type of place of work**
   a. Academic/University
   b. Hospital/Medical
   c. Private
   d. Government
   e. Other: _____________________

7. Job title

a. IRB Reviewer
b. IRB Administrator
c. IRB (Lead) Supervisor
d. IRB Manager
e. IRB Chair
f. IRB Committee Member
g. Other: ______________________

8. Level of education

a. High school diploma/GED
b. Some College
c. Associate Degree/Two-year degree
d. Bachelor Degree
e. Some Graduate Education
f. Master Degree
g. Doctorate/JD/MD
h. Other: _______________________

9. Time at current employer

a. 0-3 months
b. 4-6 months
c. 7-12 months
d. 1-2 years
e. 2-5 years
f. 5-10 years
g. +10 years

10. Time in current position

a. 0-3 months
b. 4-6 months
c. 7-12 months
d. 1-2 years
e. 2-5 years
f. 5-10 years
g. +10 years

11. **Annual earnings in current position**
    a. Less than $35,000
    b. $35,000-$50,00
    c. $50,000-$75,000
    d. $75,000-$100,00
    e. +$100,000

12. **Do you use Social Media Websites (SMWs) personally? These are websites that provide opportunities for user participation in the creation and display of multimedia data. Examples include Facebook, Twitter, Google Plus, You Tube and LinkedIn**
    a. Yes
    b. No

13. **Do you use SMWs professionally?**
    a. Yes
    b. No

14. **Tell me about your opinions of social media in general?**

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15. **Have you reviewed study *applications* that involved social media research?**
    a. Yes
    b. No

16. **Have you reviewed study modifications that involved social media research?**
    a. Yes
    b. No (Skip to 18)

17. **Can you give me an example of a study application/modification you reviewed involving SMWs?**

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18. Approximately what proportion of the total number of applications/modifications that you review includes use of social media websites?

a. Less than 25%
b. 25%
c. 33%
d. 50%
e. 75%
f. Over 75%

19. Do you have a social media policy in place that you and your team refer to when reviewing research applications and modifications that entail activity on SMWs?

a. Yes (continue)
b. No (skip to Q.28)

20. How is the policy used now by you and other staff in your IRB office?

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____

21. How do you think the policy could be improved?

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____

22. Can you please describe for me who wrote the policy? (select all that apply)

a. Chair of IRB Board
b. Board members
c. IRB manager
d. IRB supervisor
e. IRB reviewers
f. Other: ________________________

23. How long ago was the policy written?

a. 0-3 months
b. 4-6 months
c. 7-12 months
d. 1-2 years
e. 2-5 years
f. 5-10 years
g. +10 years

24. Why was the policy written? Was there a specific event or conversation that served as a catalyst to the authorship of this policy?

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25. Who has a copy of the policy? (select all that apply)

a. Yourself
b. Chair of IRB Board
c. Board members
d. IRB manager
e. IRB supervisor
f. IRB reviewers
g. Other: ________________________

26. What sources were used for forming the policy?

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27. How were these sources selected?

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28. Do you have training materials that you and your staff used to prepare for review of research involving SMWs?

a. Yes (continue)
b. No (skip to Q.40)

29. Please describe the content and format of these training materials.

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30. How are these training materials used now by you and other staff in your IRB office?

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31. How do you think the training materials could be improved?

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32. Can you please describe for me who created the training materials? (select all that apply)

a. Chair of IRB Board
b. Board members
c. IRB manager
d. IRB supervisor
e. IRB reviewers
f. Other: _______________________

33. How long ago were the training materials created?

a. 0-3 months
b. 4-6 months
c. 7-12 months
d. 1-2 years
e. 2-5 years
f. 5-10 years
g. +10 years

34. Why were the training materials created? Was there a specific event or conversation that served as a catalyst to their creation?

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35. Who has a copy of the training materials? (select all that apply)

a. Yourself
b. Chair of IRB Board
c. Board members
d. IRB manager
e. IRB supervisor
f. IRB reviewers
g. Other: ________________________

36. What sources were used for forming the training materials?

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37. How were these sources selected?

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38. Was there an in-person or online training session(s) offered?

a. Yes

b. No

39. If so, who attended this training?

a. Yourself

b. Chair of IRB Board

c. Board members

d. IRB manager

e. IRB supervisor

f. IRB reviewers

g. Other: ________________________

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40. What resources do you refer to when reviewing SMW research?

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41. How do you apply the information to your review of study submissions?

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42. Do you think your personal beliefs about social media in general influence your review of submissions including SMWs?

a. Yes
b. No

43. If so, how do your personal beliefs about social media influence your review of submissions including SMWs?

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44. How does your work load affect your ability to review study submissions in general?

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45. Does this apply to your review of studies using SMWs?

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46. What are your biggest concerns about the use of SMW's in research? Can you provide me with examples?

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47. What are the things you think are most important about using SMWs in research? Can you provide me with an example?

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48. If you could provide training to other IRB reviewers on what are the most important things to look for when reviewing social media research, or research specifically using SMW's, what would you include and why?

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49. How is your view of the risks involved when using SMWs different from the researchers/investigators whose work you review?

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50. How is your view of the risks involved when using SMW's different from other IRB staff? From the committee or board at large?

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51. As an IRB professional, how do you balance the strong demand for ethics but the need to welcome innovation?

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52. If it is out there in public, how confidential is it?

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53. Can I review materials you referred to earlier for the purpose of this research study? No identifying data about you or your organization will be included in any publications that report this data.

a. Yes (Coordinate email, mail, in-person exchange of information and timeline)
b. No

Conclusion: Thank you so much for taking the time to complete this interview.

(If in-person) I can now provide you with a $10 token of appreciation gift card if you can sign this receipt.

(If over the phone) I can now provide you with a $10 token of appreciation gift card via email or mail. Which would you prefer? (record contact information)

If you don’t have any other questions, then we will only contact you again if we need to clarify responses when we review the audio recording of this interview. We are still recruiting participants for this study. Do you have in mind a colleague that speaks English fluently and has at least 6 months of experience reviewing study applications at an IRB that you would like to recommend for this study? (if so, record contact information)

THANK YOU FOR YOUR PARTICIPATION!!!!