

# Ethics Regulation in Social Computing Research: Examining the Role of Institutional Review Boards

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## Abstract

The parallel rise of pervasive data collection platforms and computational methods for collecting, analyzing, and drawing inferences from large quantities of user data has advanced social computing research, investigating digital traces to understand mediated behaviors of individuals, groups, and societies. At the same time, methods employed to access these data have raised questions about ethical research practices. This article provides insights into U.S. institutional review boards' (IRBs) attitudes and practices regulating social computing research. Through descriptive and inferential analysis of survey data from staff at 59 IRBs at research universities, we examine how IRBs evaluate the growing variety of studies using pervasive digital data. Findings unpack the difficulties IRB staff face evaluating increasingly technical research proposals while highlighting the belief in their ability to surmount these difficulties. They also indicate a lack of consensus among IRB staff about what should be reviewed and a willingness to work closely with researchers.

## Keywords

ethics, institutional review boards, IRBs, social computing, big data

## Introduction

The ease with which researchers can engage in practices such as gathering data invisibly on the web; observing social interaction at scale; processing data using computational means such as automated sentiment analysis, natural language processing, and machine learning algorithms; and sharing data sets freely and easily online has significantly affected behavioral research. Social computing research uses such techniques to understand the technologically mediated behavior of individuals, groups, and societies. But alongside new insights about human behavior, these practices raise new questions regarding what constitutes ethical research. Such questions include the following: When is information “public” or “private” in a digital environment? What does fairness and equity for marginalized groups mean online? And, what is the role of individuals in consenting to, or more broadly participating in, social computing research processes (boyd & Crawford, 2012)?

Our previous work (Shilton & Sayles, 2016; Vitak, Shilton, & Ashktorab, 2016) has documented a growing consensus among researchers regarding what constitutes ethical research in these digital spaces and provides concrete suggestions for moving beyond the provisions set forth in *The Belmont Report*—particularly as interpreted in the United States by the Common Rule—nearly 40 years ago. However, researchers are not the only entities with a

stake in ensuring ethical research takes place in a university setting. In the United States, institutional review boards (IRBs) also play a critical role in the research process and are uniquely positioned to evaluate social computing research.

Researchers have reported that IRBs—the entities commissioned to ensure that people participating in research are protected from harm—sometimes struggle to evaluate new social computing research practices (Bruckman, 2014; Shilton & Sayles, 2016; Vitak et al., 2016). However, these reports reflect only researchers' views of the IRB, rather than the IRB's own perceptions of social computing research practices or their level of comfort evaluating research in this space. To address this gap, this article reports on how IRB staff view their ability to evaluate social computing research, their perceptions of researchers' ethical practice in social computing research, and the challenges IRBs face in ensuring adequate protections for people whose data are included in social computing research. In particular, we are interested

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in identifying agreement or disagreement about what constitutes ethical research practices in social computing research, and, taken with our previous work, where there are conflicts with researcher practices. The article first reviews the role of IRBs in U.S. academic research, and summarizes four major critiques of IRBs in the literature: misaligned goals, overly strict guidelines, problems with how informed consent is administered, and concerns about overreach. We then describe our survey of U.S. IRB administrators, which focuses on addressing these critiques in the specific case of regulating studies using pervasive, online data. Our findings not only reveal a lack of consensus among IRB staff about what social computing protocols should be reviewed but also reveal IRB administrators' willingness to work closely with researchers to make determinations. And importantly, the findings reveal internal tensions between, on one hand, a lack of expertise in emerging technologies and, on the other, experiential wisdom developed reviewing diverse research protocols. We discuss how these findings affect current critiques of IRBs, their ability to process increasingly technical studies, and the impact on governance of social computing research collection practices.

## The Role of IRBs in U.S. Research

The role of human subjects ethics committees in determining and evaluating ethical issues in research has been widely debated (Borenstein, 2008; Heimer & Petty, 2010; Schrag, 2011). Previous studies have explored the perceptions of principal investigators (PIs) toward IRBs (Edwards et al., 2012; Whitney, 2008) as well as the role ethics committee members believe they play in approving research protocols (Buchanan & Ess, 2009; Klitzman, 2011). One critique of IRBs is that overly restrictive IRB provisions lead to further misconduct by investigators (DeMaria, 2012; Swauger, 2009). Other work suggests ethics are socially constructed and, therefore, context dependent (Heimer & Petty, 2010), which raises questions about the appropriateness of IRBs applying universal standards across research populations, data collection practices, and data types.

In the following sections, we synthesize emergent themes from previous research into the role and perceptions of IRBs and researchers' perceptions of IRBs. These include discrepancies between the goals of IRBs and researchers, lack of requisite skills or domain-specific knowledge among IRB staff, issues of research-process transparency, and questions about the level to which the informed consent process can be improved. Prominent across the literature is the view that IRBs are generally understaffed and overworked, and that they should avoid focusing time and energy on low-risk research (Shamoo & Katzel, 2007). However, as highlighted by Borenstein (2008), there are challenges in determining what constitutes "low risk" research, particularly in research using pervasive data.

## Critique 1: Goals of Researchers and IRBs Are Misaligned

Unsurprisingly, discrepancies exist between what IRBs and researchers perceive as priorities in research protocol evaluation. For example, Keith-Spiegel, Koocher, and Tabachnick (2006) found that timeliness of the research protocol review process, open communication, conscientiousness, and interpersonal sensitivity were highly valued by investigators; however, these factors were less important to IRBs. Klitzman (2011) further investigated tensions between IRBs and researchers, finding that conflicts largely stemmed from misunderstandings and miscommunication. Researchers perceived that IRBs held significant decision-making power, whereas IRBs felt they did not have any real power because they were simply following government regulations.

Further complicating matters, numerous studies have found discrepancies among the types of practices viewed as ethically salient among IRBs. For example, one study found variability among IRBs regarding how informed consent forms were administered and the required reading level of consent form language (Silverman, Hull, & Sugarman, 2001). Likewise, a study by Green, Lowery, Kowalski, and Wyszewianski (2006) identified significant variations in IRBs' standards when submitting the same study for review to multiple review boards, including the classification applied to the research (i.e., exempt vs. expedited review), as well as requests for procedural and editorial revisions to the protocol. In interviews conducted with Australian ethics committee members, Guillemin, Gillam, Rosenthal, and Bolitho (2012) found that *all* members agreed the primary role of the ethics committee is to protect participants. However, qualitative responses revealed that committee members did not agree on additional roles of committee members, and there was particular disagreement regarding the relationship between IRBs' goals and those of the institution.

## Critique 2: IRBs Apply Overly Strict Guidelines to Low-Risk Research Protocols

Another major critique of IRBs is that they impose seemingly unnecessary restrictions because they lack the expertise in more technical areas such as social computing, or otherwise apply more stringent requirements to low-risk research. Schrag (2011) argues that many IRBs apply cumbersome, inappropriate principles that create significant barriers to research and encourage researchers to seek potentially harmful workarounds. He notes, for example, that many social scientists work in environments where requiring consent and participant confidentiality would prevent data collection, as in the case of sociologists who embed themselves in the research environment or

ethnographers who want to remain passive observers (e.g., Bamber & Sappey, 2007; Malone, Yerger, McGruder, & Froelicher, 2006; Neyfakh & Blumgart, 2015). The potential result of such restrictive guidelines may lead researchers to work around their IRBs. Keith-Spiegel et al. (2006) suggest that some scientists increased potential harm to research participants by intentionally deceiving ethics committees to avoid extended approval times. Likewise, Ashcraft and Krause (2007) found that 48% of researchers in one study reported collecting data or altering the research methodology without IRB approval, and offered long waiting times as the primary justification for such practices. Researchers have also argued that IRB restrictions and required changes to protocols can fundamentally change the nature of a study (Feeley, 2007) and reduce the ability to conduct transformative research. This is especially problematic when IRBs do not acknowledge how subject risk varies across disciplines (De Vries, DeBruin, & Goodgame, 2004).

Some commentators have suggested that to address critiques of IRB expertise, colleagues within researchers' home departments should evaluate the risks posed by a given research study. The logic of this argument is that researchers' home departments are best situated to evaluate the research practices in that discipline, thereby decreasing the burden on IRBs (Stark, 2007; Taylor, 2007). However, such a suggestion places significant time and resource requirements on faculty, and creates challenges ensuring such reviews enforce rigorous and appropriate ethical standards. Interpersonal or departmental politics could also complicate a department-level review process.

### *Critique 3: Challenges of Informed Consent*

One of the key components IRBs use to ensure researchers minimize participant risk is the informed consent process. Researchers have found the consent process to be one of the few areas where IRBs consistently focused their attention during the review process (Lidz et al., 2012). That said, many question the utility of current, form-based interpretations of informed consent, and improving informed consent was a major goal of the recent revisions to the Common Rule (U.S. Department of Health and Human Services, 2017). For example, Schneider (2015) says informed consent fails to achieve its purpose because participants generally do not or cannot read consent forms; even when read, participants struggle to understand and apply the information. Researchers studying disclosure policies have consistently found they do not make consumers safer (Keith-Spiegel et al., 2006).

Heimer and Petty (2010) note that informed consent is a frequent source of contention between IRBs and researchers; they suggest that introducing a more streamlined method of creating participant consent information, such as guides

for researchers, has the potential to sidestep many of the conflicts associated with getting informed consent. However, Borenstein (2008) argues that creating a standardized consent form creates additional problems because the review process will become too uniform. He suggests consent forms should instead focus on issues of clarity. Further complicating the issue of consent is research, where explicit consent prevents research from being conducted; as Schrag (2011) notes above, researchers in several social science disciplines employ methodological approaches where consent is difficult to obtain, such as ethnographers who embed themselves in their research environment. Researchers in the communication and psychology disciplines who employ deception in their studies would also face significant challenges if they were required to obtain fully informed consent from research participants.

### *Critique 4: Concerns About Overreach*

A final, sweeping criticism of IRBs is that they wield more power over institutions' research trajectory than they should, and that their power has only increased since IRBs were first instituted. Haggerty (2004) calls this "ethics creep," which he defines as "a dual process whereby the regulatory structure of the ethics bureaucracy is expanding outward, colonizing new groups, practices, and institutions, while at the same time intensifying the regulation of practices deemed to fall within its official ambit" (p. 394). This process involves each of the previously discussed criticisms and criticisms of it often use this creep to question the regulatory boundaries of IRBs. In his recently published book *The Censor's Hand*, Carl Schneider (2015) synthesizes years of empirical evidence to argue that, as currently implemented, IRBs are "bad regulation" due to fundamental flaws in how they were conceived and created.

### *Summarizing Critiques of IRBs*

There are a number of aspects of the human subjects review process that create tensions between IRBs and researchers. In some cases, these tensions may increase risks to participants, delay data collection, or substantively change a research project because IRBs apply overly restrictive guidelines developed for biomedical research to lower risk studies. Social computing research protocols further compounding these tensions, because IRBs sometimes lack the expertise to effectively evaluate technical proposals. However, the majority of the studies discussed here capture researchers' experiences and perceptions. Few works focus on the perspective of the IRB. To address this gap, we describe our project, which captures the attitudes and practices of IRBs at U.S.-based research institutions.

## Method

To study the attitudes and practices of IRB staff regarding regulating social computing research collection practices and the IRBs' ability to process increasingly technical studies, we submitted and received approval from the University of Maryland's IRB to collect data through a self-administered web survey. The survey instrument was adapted from a survey used in previous study focused on social computing researchers (Vitak et al., 2016).

The population of interest for this study was IRB staff working at U.S. universities that receive federal grant funding. We narrowed our focus to 335 university IRBs based on their classification as R1, R2, or R3 universities in the Carnegie Classification System.<sup>1</sup> Through Google searches, we identified general IRB email addresses or, when this information was unavailable, specific IRB staff members at the university for 224 institutions. The lead author directly emailed these IRB offices in May 2015 requesting that a staff member with at least 6 months experience working in that IRB office complete a 5-min survey about their policies on and attitudes toward social computing research projects.

## Measures

After providing basic descriptive information about their institution, the main section of the survey included 27 statements to which participants indicated their level of agreement along a five-point Likert-type scale (1 = *strongly disagree* to 5 = *strongly agree*, with a neutral midpoint). These items attempted to tease out IRB staff members' attitudes toward proposals involving social computing methods and/or data. Participants were also given the opportunity to respond to two open-ended responses: "What resources would you like your IRB to have available to better manage studies using online data collection?" (58% responded) and "What advice would you like to share with researchers about conducting ethical studies using online data?" (48% responded). Selected responses to these questions are included in the findings to complement the statistical analyses, though a full list can be found in the appendix.

## Data Analysis

Once the survey closed, we downloaded response data into SPSSv22 and performed data cleaning. Three cases were removed due to missing data, resulting in a final *N* of 59. To simplify the analyses, response options were collapsed from five categories to three: the two disagree options and two agree options each became one category, allowing analyses to compare those who agreed, were neutral, or disagreed with a statement. All three categories (disagreement, neutral responses, and agreement) were used as part of inferential

analysis. Note that although the scale midpoint was labeled "neutral" in the survey, we cannot infer whether participants who selected this response were indicating ambivalence, interpreting the item as context dependent, or another reason. We use "neutral" in discussing the findings to standardize how we report the data.

Because the majority of questions in the survey elicited responses on an ordinal scale, we conducted inferential statistical analyses using Fisher's exact test (FET) for independence. FET is more accurate than chi-square or G tests of independence for analyses using a small sample size (McDonald, 2015). All tests were considered significant at an alpha level  $p < .05$ .

For two open-ended items ("What resources would you like your IRB to have available to better manage studies using online collection?" and "What advice would you like to share with researchers about conducting ethical studies using online data?"), responses were first exported to Excel spreadsheets. Three of the authors independently coded responses for emergent themes. The lists of codes were compared and a final set of codes was generated (nine for the resources question and 10 for the advice question). The responses were then coded a second time using the agreed-upon list of codes by each author.

## Limitations

We acknowledge that, as with any survey instrument, it is possible that respondents misrepresented their views. However, the inclusion of open-ended follow-up questions in the survey gave respondents a chance to provide greater depth and nuance to their responses. Although alternative designs that relied on more open-ended questions and fewer Likert-type scale responses were considered, participant fatigue from that structure could have resulted in a loss of valuable breadth and diversity in the data. In terms of the reliability of the survey instrument, as noted previously, it was adapted from a survey instrument that captured novel insights about researchers' positions regarding the regulation of social computing research. After piloting the survey with a small group of colleagues and adjusting it as per their recommendations, we believe the original survey has been effectively adapted to capture novel insights about IRB attitudes and practices regarding the regulation of social computing research. Finally, the findings that we present here are limited in their generalizability to U.S. research institutions. As the IRB structure and relevant regulatory frameworks vary globally, it remains unknown to what degree the findings from this work might be representative of research ethics bodies outside of the United States.

## Findings

After three reminder emails over the following 4 months, we had received responses from 62 unique universities

(response rate = 28%) from 32 states. Among the 59 fully completed surveys, responding institutions, 32 (54%) identified themselves as an R1 campus and 27 (46%) identified as an R2/R3. Compared with the population of universities invited, IRB staff from R1 institutions are overrepresented in the sample, whereas IRB staff at R2/R3 institutions are underrepresented.<sup>2</sup>

Below, we summarize results from our descriptive and inferential analysis across four conceptual areas: IRB staff's self-evaluation of their ability to regulate social computing protocols, their views of social computing researchers, and their views on the ethics of social computing research practices. We also briefly discuss where statistically significant differences emerged based on university types (R1 vs. R2/R3 and public vs. private institutions). We highlight these thematic areas because they document ways in which the critiques of IRBs do (and do not) apply to social computing research, and offer the richest possibilities for creating a dialogue between social computing researchers and IRBs.<sup>3</sup>

### *IRBs' Self-Evaluation of Technical Competency*

Almost all IRB staff members surveyed agreed (93.1%) that there are ethical issues unique to research using online data. However, only half of respondents (55.2%) said they felt their IRBs are well versed in the technical aspects of online data collection, whereas slightly more than half (56.9%) agreed that their IRB has the expertise to stay abreast of changes in online technology. Despite this, nearly three quarters (71.2%) of IRB staff agreed with the statement, "IRBs can determine potential risks to study participants from online data collection." This suggests staff members generally feel confident in assessing study risks, even when they doubt their IRB's knowledge about, and ability to keep up with, technological advancements. This finding is complemented by qualitative responses to the question asking staff to identify resources they would want to better do their job. Several participants said they had all the resources they needed, although the majority of these responses included the caveat that their IRB currently had the staff or resources to stay abreast of technological advances.

Subsequent FETs of the agree/neutral/disagree responses revealed several self-evaluation responses were significantly correlated with responses to questions about research practices on the survey, suggesting relationships between self-evaluation and regulation decisions. For example, response to the prompt "IRB staff members at my institution are well-versed in the technical aspects of online data collection" correlated with views about the necessity of consenting research participants. This included the following: "Scraping data from online sites requires informing subjects at some point during study" ( $p = .012$ , FET) and "Researchers can still collect large-scale online datasets if they are required to obtain informed consent from subjects"

( $p = .002$ , FET). Respondents who believed their IRB staff is not well versed in the technical aspects of online data collection were more likely than expected to *disagree* that scraping from online sites requires informing subjects. Increased confidence about technical literacy correlated with stricter definitions of when consent is required. Belief about the IRB's technical literacy also correlated with responses to the prompt: "Studies in which researchers scrape public data from the web should always be evaluated by IRBs" ( $p = .003$ , FET). Interestingly, those who gave a neutral response as to whether their IRB's staff members are well versed were *more likely* than expected to remain neutral about whether studies in which researchers scrape public data from the web should always be evaluated by IRBs. Although it is possible that IRBs without strong technical expertise recognize the contextual nature of research projects using digital trace data, a more likely explanation for this correlation is that uncertainty about technical expertise relates to more general uncertainty in evaluating proposals using technical methods or data.

### *IRBs' Views of Researchers*

**Researcher reflexivity.** The survey revealed that IRB staff members have divergent opinions about researcher reflexivity. When asked whether they think researchers collecting online data thoughtfully consider the implications of their data collection, 32.8% agreed, 25.9% disagreed, and 41.4% indicated neutrality. Likewise, when asked whether they think researchers collecting online data focus enough on ethical questions related to their research, 24.1% agreed, 34.5% disagreed, and 41.4% indicated neutrality. These response patterns suggest many IRB staff are somewhat skeptical of researchers' reflexivity. However, when given the statement "Most researchers at my institution are concerned with the privacy of subjects in their studies," a clear majority (81.0%) of respondents agreed. This suggests that IRB staff find privacy, in particular, to be a well-recognized issue for researchers.

The survey also provided insights into IRB staff members' opinions about researchers' ethics-review practices. For example, when given the statement, "I think researchers collecting online data *all* consult with the IRB before beginning data collection," only 22.4% of respondents agreed, whereas 55.2% disagreed and 22.4% indicated neutrality. However, a majority of respondents (81.0%) agreed that researchers at their institution consider the ethical aspects of online data collection *in their IRB applications*, suggesting that IRB staff view these applications as a lever for ethical reflection.

**Researcher responsibility.** A majority of respondents believed researchers are held to a higher ethical standard than others who use online data (53.4% agreement), and a majority

(51.7%) also believe that they *should be* held to these higher ethical standards. When asked whether researchers collecting online data are more likely to consider ethics of their data collection now than they were several years ago, a clear majority (69%) agreed. However, responses to the statement, “I think researchers collecting online data are more interested in data than the people behind the data,” were more ambiguous, with 40.4% of respondents agreeing, 19.3% disagreeing, and 40.4% indicating neutrality.

### IRBs Staffs’ Views on Research Practices

**Need for review.** IRB staff expressed divergent opinions regarding their role in evaluating online research. Although nearly all respondents (89.7%) agreed that data scraping projects should be evaluated on a case-by-case basis, when asked whether studies scraping web data should *always* be evaluated by IRBs, 33.3% agreed, 42.1% disagreed, and 24.6% indicated neutrality. Likewise, when asked whether online data sets without identifying information do not need IRB approval, 31.0% agreed, 62.1% disagreed, and 6.9% were neutral. Finally, when asked whether researchers collecting online data should always run their research plans by IRBs, *even if they do not meet the IRB standards for requiring review*, 50.0% agreed, 31.0% disagreed, and 19.0% were neutral. These response patterns suggest an *overall lack of consensus* on the kinds of research practices that should trigger IRB review.

**Informed consent and notification.** Few respondents (5.3%) agreed that scraping data from online sites requires obtaining informed consent from subjects prior to data collection (40.4% disagreed, 54.4% indicated neutrality). When the wording of the prompt changed to “informing subjects at *some point* during the study”—reflecting the idea of notice rather than consent—response rates shifted slightly, with 19.3% agreeing, 26.3% disagreeing, and 54.4% indicating neutrality.

Qualitative responses in the survey highlighted risk evaluation as one of the key factors IRB staff focus on when evaluating applications and making determinations about requiring informed consent—or even requiring a formal review. One participant noted,

There’s a difference between conducting an on-line study where the potential participants are informed of the purpose and risks/benefits, and scraping already available data that is on a public site. For the second case, [researchers need] a better understanding of what is “public” and what isn’t. It’s difficult to determine privacy expectations of users of social media, when everything posted is to some degree public.

### Institutional Characteristics

Only three statistically significant relationships between institutional characteristics and responses to the Likert-type

scale survey items emerged in analyses. First, respondents from R1 universities were more likely than expected to disagree and R2/R3s were more likely than expected to agree with the statement, “I think researchers collecting online data should always run their research plans by IRBs, even if they do not meet the IRB standards for requiring review” ( $p = .04$ , FET). This suggests IRBs at R1s may see themselves playing less of a role in advising research projects that do not qualify for review than IRBs at non-R1 institutions.

Staff at R1s were more likely than expected to disagree and staff at R2/R3s were more likely than expected to indicate neutrality when prompted, “I think researchers collecting online data are more likely to consider ethics of their data collection now than they were several years ago” ( $p = .002$ , FET). One explanation for this is that R1s have longer experience with social computing research proposals and have seen consistent levels of ethical concern, whereas institutions with less focus on research may only now be reviewing these types of projects. Finally, public institutions were less likely than expected to agree whereas private institutions were more likely than expected to agree with the prompt, “Scraping data from online sites requires obtaining informed consent from subjects before beginning data collection” ( $p = .03$ , FET). This suggests that IRBs’ procedures for determining when consent is needed in social computing projects may vary by institution.

## Discussion

Taken together, the findings from this study highlight three major themes: a lack of consensus among IRB staff about what should be reviewed, a willingness to work closely with researchers, and internal tensions between, on one hand, a lack of expertise in emerging technologies and, on the other, experiential wisdom developed reviewing diverse research protocols. We discuss each of these below.

### Lack of Consensus on Review Necessity and Standards

As evidenced in the findings, IRBs hold a range of opinions regarding what projects researchers should submit for review. For example, some staff indicated a desire to review projects that scrape public data, whereas others expressed no desire to review this type of project. Furthermore, there were conflicting opinions among IRB staff about whether approval is needed when researchers are not collecting identifying information about subjects from online data sets. These contradictory views are in line with published research critiquing IRBs for a lack of consistent evaluation standards (e.g., Green et al., 2006). One could interpret these findings as evidence that IRB staff lack the necessary skills and knowledge to effectively apply the Common Rule to data-centric human subjects research. A more likely

interpretation is that the Common Rule itself does not provide appropriate guidance for the realities of research with online data. Most IRB staff expressed a desire to provide clear ethical guidelines to researchers and to receive clear guidelines for evaluating social computing research from the federal government. Such guidelines would benefit both the researchers conducting these studies and the IRB staff evaluating applications.<sup>4</sup> When asked whether they had advice to offer researchers, one IRB staff member shared the honest assessment, “No advice available. Still struggling with this,” highlighting the challenges IRBs across the United States face when evaluating diverse research proposals.

At the time of writing, the U.S. Department of Health and Human Services (HHS) and 15 other U.S. federal agencies had recently published their update to the Common Rule, which will go into effect in January 2018. This update is meant to “better protect human subjects involved in research, while facilitating valuable research and reducing burden, delay, and ambiguity for investigators. These revisions are an effort to modernize, simplify, and enhance the current system of oversight” (Federal Register, 2017). For social computing researchers, the most important changes (a) establish new requirements regarding information that must be given to prospective research subjects as part of the informed consent process; (b) allow the use of broad consent (seeking prospective consent to unspecified future research) for data storage, maintenance, and secondary research use of identifiable private information; and (c) establish new exempt categories of research based on their risk profile. Under some of the new categories, exempt research would undergo limited IRB review to confirm that researchers have implemented adequate privacy safeguards for identifiable private information. Whether these changes will address our participants’ concerns has yet to be determined.

We also believe that a lack of consensus around review might be an artifact of our data collection process, which asked about generalities rather than specifics. We believe that many IRB staff recognize the complicated and context-specific nature of online data projects, which is why their responses trended toward wanting to review projects on a case-by-case basis. Furthermore, as highlighted in the findings from an analysis of social computing researchers’ attitudes and practices (Vitak et al., 2016), achieving consensus for “bright-line” rules may be impossible. That said, we see many areas for improving understanding and reducing miscommunication between IRBs and researchers, which we expand upon below.

IRB staff struggle to define not only what methods should merit review but also what protection mechanisms social computing studies should have in place for the people behind the data. Respondents were overwhelmingly neutral about whether scraping data from online sites required

obtaining informed consent. Neutral responses may reflect staff’s belief that such decisions are context specific, or that they are ambivalent, uncertain, or simply do not know due to lack of experience. From the qualitative data, we know that at least some of the IRB staff surveyed struggled to respond to questions because their responses would vary based on the specifics of an application. For example, one participant wrote,

Note to Researchers: the blank questions are because it is situation specific. Not all big data studies include deductive re-identification and even if the individual’s identification can be discerned by the researchers, it is not always reported in a way that consumers of the research can make deductive re-identification.

This comment reflects one of the largest challenges IRBs face when evaluating research using new methods or collecting data from online sources: the considerable variation between studies on factors (such as reidentification potential) that matter to ethics review.

### *Aligning Goals With Researchers*

Beyond the lack of consensus across review boards in the United States, there was one topic where IRB staff’s attitudes were at odds with social computing researchers—the ability to collect consent from large-scale data projects. Very few respondents disagreed with the claims “It’s possible to obtain informed consent from participants before conducting large-scale online studies” (15.5%) and “Researchers can still collect large-scale online datasets if they are required to obtain informed consent from subjects” (17.2%). However, this finding runs counter to the views of social computing researchers, as identified in Vitak et al.’s (2016) study. In that survey, 35.1% of social computing researchers agreed that it is possible to obtain consent, whereas the largest subset (40.3%) disagreed. A similar, negatively valenced item (“I do not think researchers could collect large-scale online datasets if they were required to obtain informed consent from participants”) yielded similar differences between researchers and IRB staff, with 56.2% of social computing researchers agreeing with this statement. Such discrepancies highlight the need for bridging dialogue between researchers and IRBs around the topic of informed consent. It is important to note that IRB staff expressed willingness in the survey to work toward alignment with researchers. For example, one respondent wrote, “talk with your IRB—educate them and the staff to enable you to reach your research goals without sacrificing your research participants (i.e. increasing their risks) along the way!”

By creating partnerships with faculty, IRBs have the opportunity to update their guidelines to better reflect the

changing data collection landscape. Attempts at such updates have been previously made, most notably in the Menlo Report (Dittrich & Kenneally, 2012), which was collaboratively written by more than a dozen technology and ethics specialists across academia, industry, and policy to “help clarify how the characteristics of ICT raise new potential for harm and to show how a reinterpretation of ethical principles and their application can lay the groundwork for ethically defensible research” (Dittrich & Kenneally, 2012, p. 1). Many IRB staff in our study expressed aspirations to partner with researchers and to be actively involved in helping shape research practices in this space. A clear majority of IRB staff said social computing researchers need to work with IRBs to develop standards for online data collection, and many respondents said they lacked the technical expertise to be able to evaluate these projects. These findings provide another avenue for creating dialogue—an opportunity for the social computing community to help IRBs meet their aspirational goals.

One obvious barrier to achieving such a partnership is moving researchers beyond the view that IRBs are an antagonistic entity in the research process. The majority of previous IRB-focused research dwells on researcher complaints, including long review times, unnecessary protocol changes, or overly restrictive terms that prevent data collection based on a misunderstanding of potential risk to participants (De Vries et al., 2004; Heimer & Petty, 2010; Schrag, 2011). Although increasing the number of faculty in technical disciplines who serve on IRB committees is an easy way to directly address these perceptions—and highly desired by IRB staff—such efforts will necessarily compete with limited faculty time and attention. Alternative bridges can be built between these two communities through developing knowledge exchange programs, where social computing researchers can discuss their methods and the tools they use with IRBs, and IRBs can address the most important participant risks inherent in collecting digital trace data. However, this may require institutional-level organizing and incentive structures to engage faculty. That said, ensuring human subjects’ research meets ethical and legal guidelines should be a pressing priority for researchers. In addition, IRBs should prioritize increasing knowledge and defining standards for social computing research. An IRB staff member in our study commented on such a need for more system-wide discussions, saying, “I would love it if professional IRB organizations (like PRIM&R) would have a day long conference addressing [data security] issues.”

### Wisdom, Experience, and Regulation

Finally, underlying many of the response patterns seen in this study are tensions between two sets of dynamics: first, IRBs’ federally mandated role to enforce the Common Rule vying with their aspirational goals of providing context-appropriate

guidance; and second, IRBs’ concerns about staying technically informed balanced against their confidence borne from experience evaluating diverse research protocols.

IRBs are clearly struggling to balance enforcing federal regulations with evaluating studies in context-appropriate ways. It is important for IRBs to acknowledge that the guidelines laid out in the Belmont Report and Common Rule were devised to address concerns about risks to participants in psychological and biomedical studies, especially those using deception. Although social computing data collection methods have introduced new participant risks through reidentification in a data set (see Zimmer, 2010, for one example), the risks to participants are usually smaller than in biomedical contexts, in particular, and should require a separate set of evaluation criteria.

### Educational Implications

We believe that when IRB staff express a desire to evaluate studies on a case-by-case basis, they are making an appeal to the practical wisdom they have developed through experience. Referred to as *phronesis* in ethics (Ess, 2009), practical wisdom can be a critical part of ethical decision making. Understanding the true risks to participants in social computing research, for example, will require the development of practical wisdom over time by considering many cases, kinds of risks, and potential consequences. And, there may be no one better on a campus to practice *phronesis* than IRB staff, who review hundreds—or thousands—of diverse research protocols yearly. Opportunities for sharing institutional knowledge and past experiences should be incorporated into industry-specific events such as Public Responsibility in Medicine and Research (PRIM&R) so that IRB staff from diverse institutions have the opportunity to learn from each other’s experiences with reviewing social computing research proposals.

### Best Practices

This study reveals trends in IRB staff members’ self-evaluation, views on researchers, views on research practices, and aspirations. Findings highlight tensions around a lack of consensus over the IRB review process, including what types of social computing research should be evaluated by IRBs, the challenge of obtaining informed consent in large-scale data projects, and between IRBs’ regulatory obligations and the desire to evaluate research protocols in context-specific ways. These tensions point to key areas for IRBs to partner with the social computing community on revising and improving ethical guidelines. As a whole, IRB staff view researchers as valuable potential partners in fostering ethical research practices. For such a partnership to

succeed, however, both parties must be prepared to accept additional responsibilities for ensuring participants are treated fairly and ethically.

A recent law review article authored by members of Facebook's policy team (Jackman & Kanerva, 2016) effectually summarizes how ethics reviews must evolve in light of changing research methods. The authors write,

A flexible process is key: The ever-changing nature of the questions and data involved in industry (and academic) research requires that any processes must be able to adapt efficiently to new internal challenges and external feedback so they can improve over time. (Jackman & Kanerva, 2016, p. 444)

To achieve this goal of flexibility, we believe the best path lies in creating environments that foster dialogue between these stakeholders and, subsequently, promote better outcomes for

all stakeholders, including social computing researchers, IRBs, and research participants.

## Research Agenda

As with any self-administered survey, there is the potential for respondents to misrepresent their views or practices. Furthermore, our sampling methodology necessitated asking a single staff member to respond for their IRB as a whole. It is difficult to say whether the same response patterns would be seen if different members of the same IRB gave responses. We also acknowledge the relatively small sample size of our survey. Although our work offers an initial inroad toward fostering dialogue between social computing researchers and IRBs, future research should endeavor for more comprehensive surveys of IRBs. Finally, longitudinal survey and analysis with a standardized set of IRB members would help trace how attitudes, beliefs, and practices change over time.

## Appendix

Please indicate the extent to which you agree or disagree with the following statements.

Prompt	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Total
There are ethical issues unique to research using online data.	0	2	2	30	24	58
IRB staff members at my institution are well versed in the technical aspects of online data collection.	2	10	14	29	3	58
Researchers at my institution consider ethical aspects of online data collection in their applications.	0	6	5	40	7	58
The ethics of online data scraping should be evaluated on a case-by-case basis.	0	2	4	36	16	58
Scraping data from online sites requires obtaining informed consent from subjects before beginning data collection.	2	21	31	2	1	57
Scraping data from online sites requires informing subjects at some point during study.	0	15	31	9	2	57
My IRB has the expertise to stay abreast of changes in online technologies.	1	10	14	26	7	58
Most researchers at my institution are concerned with the privacy of subjects in their studies.	0	3	8	36	11	58
Studies in which researchers scrape public data from the web should always be evaluated by IRBs.	2	22	14	17	2	57
Researchers can guarantee the anonymity of subjects in an online data set.	10	30	12	4	1	57
Researchers who do not collect identifying information about subjects from online data sets do not need IRB approval.	11	25	4	17	1	58
IRBs should have clear ethical guidelines for researchers engaged in online data collection and analysis.	0	3	1	31	23	58
Research with online data provides new opportunities for engaging research subjects in the research process.	0	1	9	34	14	58
Research with online data provides new opportunities for engaging research subjects with research findings.	0	2	7	34	15	58
I think researchers collecting online data all consult with the IRB before beginning data collection.	5	27	13	12	1	58
I think researchers collecting online data thoughtfully consider the implications of their data collection.	0	15	24	16	3	58
I think researchers collecting online data should always run their research plans by IRBs, even if they do not meet the IRB standards for requiring review.	2	16	11	26	3	58
I think researchers collecting online data are mindful of how their research practices may affect marginalized individuals within their research population.	0	21	17	17	3	58
I think researchers collecting online data focus enough on ethical questions related to their research.	0	20	24	13	1	58
I think researchers collecting online data need to work with IRBs to develop standards for online data collection.	0	2	4	43	9	58

(continued)

## Appendix (continued)

Prompt	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Total
I think researchers collecting online data are more interested in data than the people behind the data.	0	11	23	21	2	57
I think researchers collecting online data are more likely to consider ethics of their data collection now than they were several years ago.	1	8	9	34	6	58
Researchers are held to a higher ethical standard than others who use online data.	1	11	15	23	8	58
Researchers should be held to a higher ethical standard than others who use online data.	1	16	11	23	7	58
It is possible to obtain informed consent from participants before conducting large-scale online studies.	1	8	23	23	3	58
IRBs can determine potential risks to study participants from online data collection.	0	1	15	38	4	58
Researchers can still collect large-scale online data sets if they are required to obtain informed consent from subjects.	0	10	19	25	4	58

Note. IRB = institutional review board.

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### Notes

1. See <http://carnegieclassifications.iu.edu/>
2. Although we are unable to tease out the reason for these skewed completion rates, it is possible institutional review board (IRB) representatives more familiar with online data research were more likely to participate in the study than those for whom this kind of research was more rare.
3. A table of the descriptive results from the questions can be found in the appendix.
4. Such guidelines seem unlikely to be forthcoming. The new Health and Human Services recommendations, if adopted, do not discuss digital data explicitly, and give more decision-making authority for defining risk to individual institutions (U.S. Department of Health and Human Services, 2017).

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