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## *The Ethical Disruptions of Social Media Data: Tales from the Field*

*Susan Halford*

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### *Abstract*

This chapter explores the perfect storm brewing at the interface of an increasingly organised ethics review process, grounded in principles of anonymity and informed consent, and the formation of a new digital data landscape in which vast quantities of unregulated and often personal information are readily available as research data. This new form of data offers huge potential for insight into everyday activities, values and networks but it also poses some profound challenges, not least as it disrupts the established principles and structures of the ethics review process. The chapter outlines four key disruptions posed by social media data and considers the value of situational ethics as a response. Drawing on the experiences and contributions of PhD students in interdisciplinary Web Science, the chapter concludes that there is a need for more sharing of the ethical challenges faced in the field by those at the 'cutting edge' of social media research and the development of shared resources. This might inform and speed-up the adaptation of ethics review processes to the challenges posed by new forms of digital data, to ensure that academic research with these data can keep pace with the methods and analyses being developed elsewhere, especially in commercial and journalistic contexts.

### *Introduction*

Over the past 30 years the ethics landscape for social research has undergone some fundamental changes. Even as recently as the late 1980s - when I started my PhD - there were no formal ethics procedures for social scientists, at least where I was working. This is certainly not to say that, as researchers, we didn't consider the ethics of our research but rather that we relied on our own judgement and on the norms of practice in our field, amongst our peers and on the advice of our supervisors to guide our practice. Mostly very sensible decisions were made but so too some extraordinary things were done, and some ill-considered were risks taken, at least by today's standards. Overall, in my experience, research practice appeared to be broadly ethical — but by individual disposition, cultural environment and (sometimes) by luck, rather than by design.

Over the intervening years there has been a progressive organisation and bureaucratisation of UK University research ethics: the establishment of standardised rules and procedures, using specified forms and checklists, within institutionalised workflows and hierarchies of decision making. The roots for this lie at last as far back as the 1960s, with calls for the introduction of an ethics review process in biomedical research (Kerrison and Pollock 2005) with attention to the issue filtering slowly into individual Universities, including into the social sciences (Tinker and Coomber 2005). By 2003 the Economic and Social Research Council began the process of

establishing a Research Ethics Framework<sup>1</sup>, which was introduced in 2006 and rapidly became established as the benchmark across social science research and – in particular – prescribed a governance framework for institutions wishing to receive ESRC funding (strengthened by updates in 2010). Alongside this, the UK Universities Research Ethics Forum was established in 2005 as a sector-wide group for sharing experience and practice and the UK Research Integrity Office was launched in 2006. The UK ethics governance structure continues to develop, with the publication in 2012 of the Concordat to Share Research Integrity by a consortium of University and Government research agencies), followed the Economic and Social Research Council's own more specific and updated Framework for Research Ethics in 2015. Within this infrastructure, appropriate standards of practice are defined, within a professional framework that provides layers of protection for the researchers and institutions involved. In the interests of our participants, contemporary ethics processes seek to ensure rights, protection from harm and an active voice in the research process. These processes also protect the researcher from potentially risky situations, and the harms that might result, and from legal liability so long as research is conducted as proposed. In turn, this protects the status, corporate reputation and financial interests of the universities and research institutions. In Weberian terms these standardised rules offer a progressive means towards efficiency and fairness (Weber 1964; Clegg 1990). In more Foucauldian terms, we might also see these changes as part of a shift in the wider organisational discourse, as a new assemblage of values and practices are institutionalised as the 'right and proper' values, standards and practices, where the possible ways of ethical social science research have been narrowed to the 'best' way of ensuring ethical research and, it can seem, presented as the 'only' way of achieving this. We might think here of informed consent, anonymisation and individual protection from harm – the gold standards of the social science ethics regime, echoing the original concerns from biomedicine (Neuhaus & Webmoor 2012; Kernaghan 2014; Zwitter 2014).

Meanwhile, as these processes were underway, so too was a remarkable set of changes in the nature of the data that social researchers have available to them. As public applications for the internet began to take-off in the 1980s, e-mails, bulletin boards and UseNet groups became a rich new source of 'found' data for researchers (Sproull and Kiesler 1986, Rafaeli and Rose 1993, Rheingold 1993, Dery 1994). But this was nothing compared to what came next. In 1989 Tim Berners-Lee wrote a memorandum proposing a new global information sharing system that would come to be known as the World Wide Web. Berners-Lee's original motivation was to find a means through which researchers working in remote teams could share data more easily, using standardised protocols on top of the internet (Berners-Lee 2000). This was a rather successful idea, of course, with the number of web pages rising from zero in 1990 to almost a billion today<sup>2</sup>: a significant source of information for researchers across the academy, as well as for governmental and independent research institutes. However, by the mid-2000s it became clear that this too was just the beginning. What had started as a means of *sharing* data was becoming a means of *generating* data – 'big data' – of a variety, scale and velocity unimaginable in 1989. We might think for example of the all the browser searches and link-clicks that can be captured as the digital traces of our preoccupations and preferences as we surf the Web and which are

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<sup>1</sup> <https://www.york.ac.uk/res/ref/documents.htm> Accessed 04/04/17

<sup>2</sup> <http://www.internetlivestats.com/total-number-of-websites/> Accessed 17/10/16

fuelling a new data economy (Mayer-Schönberger and Cukier 2013). Unfortunately, few of these data are accessible to researchers (outside of the corporate giants that own them). However, the evolution of the Web from ‘read only’ to a ‘read-write’ Web that was both driven by and fuelled the take-off of social media has generated another remarkable new source of data for social research, some of which is readily available to researchers, online and at no cost (e.g. from Twitter, Instagram, and YouTube). These data provide digital traces of the everyday, at an individual and often a remarkably intimate level of detail. As Latour (2007: 2) has remarked ‘... *it is as if the inner workings of private worlds have been pried open*’.

So we have a perfect storm. On one side, we have the cumulative bureaucratisation of research ethics review processes, shaped by a particular set of discourses that define appropriate research practice. On the other a radical transformation in our data landscape through processes that fall outside of the remit of our formalised ethics processes and which disrupt the bureaucracy of ethical practice in its current form and the discursive formation that supports this. These disruptions have become increasingly apparent for those of us working with social media data across the academic field and – more locally – for us in the Web Science Institute, at the University of Southampton, UK, where we undertake a wide range of research with social media across the disciplines, in particular through the Centre for Doctoral Training in Web Science. The following discussion is grounded in this practical experience, organized into three sections. Section 1 outlines in principle five of the key ethical disruptions posed by the use of social media data in social research. Section 2 considers some of the consequences of these as they appear in the practice of research, including the turn to situational ethics. Building on this Section 3 suggests how the practice of situational ethics might be supported. These observations draw on my own experience, on discussion with colleagues over the years and, in particular, on the contributions of PhD researchers working at the cutting edge of research with social media data under the interdisciplinary umbrella of Web Science.

### *Disruptions*

In what follows, I outline five ethical disruptions that have arisen in the context described above. These are grounded in our experience. It is, no doubt, an idiosyncratic list and is intended as a starting point, rather than a finished description. In order to develop our understanding of the ethical issues involved in using social media data, researchers will need to share experiences and explore the points of overlap and difference. Important points of difference to consider will include sensitivity to both the different types of data that we use, and the questions that we ask of these data.

**I *These data are already created:*** our current ethics regime, and its associated bureaucracy, assumes (very largely) that we are seeking approval to generate *new* data. The existing assumption is that we design the methodology, we negotiate the terms of access, and we deploy the methods that turn our research into ‘generated’ data. We control the means of production, so we can ensure that this is ethically done. We know who the participants will be, will avoid unnecessary exclusions/appropriate inclusions or protect vulnerable groups, won’t ask about certain things, will seek informed consent, ensuring that our participants understand their right to withdraw, and we won’t conduct covert research (or almost never unless safe, secure and absolutely necessary). In contrast, social media data are already produced and can be deeply personal. We

don't always know for sure who has produced them or their age or status in terms of the categories of vulnerability we are used to (under 18, unable to give consent, and so on) or, from a more formal, legal perspective, the jurisdictions in which they are produced. And whatever the data were produced for, however much the intention may have been to make a public expression of creativity or to 'be seen' (at least at the time) users' knowledge and understanding of whether their social media posts are 'data' are uneven and their views on the re-use of this material are complex (Beninger et al 2014; Evans et al 2015).

**II *These data are beyond our control:*** in completing research ethics review applications we promise to care for our data, keeping them in a locked filing cabinet and on servers behind the University firewall and password protected computers. This is underpinned by the assumption that what happens to the data is in our power and that we can use that power to behave ethically. So, we are assumed to be able to guarantee confidentiality and anonymity to our participants, ensuring that no personal details are made public, because no-one else has access to the data to interrogate it. An exception to this is the (increasing) expectation or even requirement from funders that data be made available through archives for secondary analysis but even then it is possible to make the argument that the sensitive nature of particular data sets makes them unsuitable for deposit. If we do deposit our data we can redact sections to exercise control over anonymization, and the full individual level data sets – qualitative data sets especially – are rarely (as yet) published in their entirety online. In short, the current ethics regime assumes that we can and should make effective assurances to participants about what happens to their data. In contrast, social media data are already published, available to anyone, and computational methods can compare incomplete data to similar data sets published elsewhere, and/or cross reference with other related data sets, at scale and speed, making irreversible anonymization nigh on impossible, especially if we consider the possibilities of as yet un-invented methods for reverse engineering.

**III *These data are not finite*** The current ethical regime presumes a bounded data set, with rules that apply internally to that data set and what we do with it. But the digital nature of these data and distributed access to them changes what can be done with them and by whom. Social media data have a social life of their own, beyond their re-purposing as research data, circulating in timelines, retweets and online conversation, for example, and may change status over time, for example as a user deletes content, radically extending the principle of the 'right to withdraw' from research beyond the lifetime of a project to potentially in perpetuity. This raises new ethical questions and challenges in terms of implementing ethical commitments, not least as the provenance of data – past and present – may be difficult to track, or even to discover. There is also the linked issue of the potential for linkage of digital data. The capacity to combine large data sets can reveal intimate details of individuals' lives – things they may not even have told their friends or families – and can be used to generate new social categories that may contain biases or, at least, have consequences for individuals' life chances (Jernigan and Mistree 2009; Pasquale 2015). This raises questions about the ethical boundaries of our own actions, as researchers, but also the opportunities for others to combine our data with other sources, potentially with the intent to de-anonymise (as above) or (perhaps more likely) with the intent to pursue new research questions that might inadvertently de-anonymise (Crawford and Schultz 2013).

**IV** *There are some implicit assumptions about scale and granularity* which shape how the ethical relationships with research participants is conceptualised within the existing ethics review regime. We are used to relatively small sample sizes – maybe in the tens for qualitative research, the hundreds or low thousands for quantitative research. This means that we can have (close) relationship with our research participants: they know who we are and we know who they are. Often we can speak to our participants, discuss the research with them and offer feedback on our findings. For larger scale research we are still able to inform, offer information on our lines of accountability, and offer feedback. The scale of social media data reduces the possibility of a direct relationship between researchers and these ‘participants’ (even the term seems inappropriate – are they ‘authors’, ‘text creators’ or ‘data subjects?’). At least, we do not currently have established methods to support this. Furthermore, in the existing ethics regime, the level of granularity is protection of the individual (see Zwitter 2014 for a good discussion of this). Yet the social nature of social media data means that one of its most attractive elements is the trace of social interaction that these data provide and, of course, their digital nature makes it possible to trace this at scale in ways that have never been possible before. Similarly, the digital nature of these data also makes it possible to interrogate and combine in order to explore and delineate social groups. This is well established in the field of marketing (Webber et al 2015), also in surveillance (Lyon 2014) and raises questions about the ethical boundaries for social researchers.

**V** *These data are attracting interest in social research from across the entire research field:* where once social research required the specialist expertise of social scientists, who honed particular techniques to collect data (Savage 2010), the emergence of these new forms of data require expertise more commonly found in the mathematical and computational sciences who can engage with these data in ways that most social scientists cannot (Savage 2010; Tinati et al 2014). This disciplinary disruption means that social research is moving into new disciplinary jurisdictions and meeting new ethical regimes that look different to those we are familiar with. Here we see profound differences between how the computational sciences regard social media data – as published, in the public realm and therefore not in need of ethical regulation – and how we as social scientists see this, coming as we do from principles of informed consent, anonymization and individual protection from harm.

### *Consequences*

So, here is the problem: our established ethics regime reveals itself to be constructed on the basis of particular types of data, and disciplinary settlements but we are faced with new forms of data which do not fit neatly into established practice, and an associated unsettling of the disciplinary boundaries. This has some profound practical consequences for researchers using social media data. Indeed, consultation with our PhD researchers identified the single biggest challenge of working with social media data as *the ethics process itself* which demands advance precision on the ethical contours of research, where these may be hard to determine:

*With social media research, one of the things I have observed is that institutional processes for establishing formal ethics for research projects tend to focus on static statements which do not allow for the incorporation of flexibility that is necessary when studying group activities online. **Nicole Beale**<sup>3</sup>*

There was concern that, on occasion, the process itself may become a tokenistic hurdle, rather than a constructive way of supporting research in the field:

*There is procedural over-emphasis on trying to cover all corners which tends to encourage (well-meant) guess-work just to get a green light; worse it can encourage non-disclosure to avoid edge cases. Less well imbued in the current process is the importance of considering what you do when encountering the unforeseen. A paternalistic 'no colouring outside the lines' approach lets the legal department sleep at night but may not aid research. **Mark Anderson***

And, worse, that the current process did not fully understand the technical issues

*Researching forums on Tor focusing on the sale of illicit goods has been my biggest ethical challenge ... In my opinion the lack of understanding of underground forums/ marketplaces of the ethics committee slowed my research down a bit. **Geert Van Hardeveld***

Or the changing nature of the data landscape:

*I think for me the biggest ethical challenge is ... the gulf between the practice of ethics as exemplified by the [formal] process and the reality. In completing [the ethics process] I promise to do things I know I am technically unable to do - I cannot truly delete all the personal data held at the end of the project ... it would not take much effort to re-identify anonymised data ... the process [of ethics review] is possibly the most ethically-compromising part of my research. That's not right.' **Jo Walker.***

These experiences are echoed in a recent survey of researchers using social media data commissioned by the ESRC in 2015, which found that fewer than 10% of respondents felt that the current ethics guidelines were adequate for their research<sup>4</sup>.

It is in this context, that a turn to *situational ethics*<sup>5</sup> has emerged. With roots in virtue ethics and a feminist ethics of care, situational ethics emphasises the dialogical and relational process of ethical responsibility (Cupurro and Pingel 2002) and the emergent nature of both ethical challenges and ethical responses in social research. In contrast to the deontological and consequentialist emphasis that underpins current research ethics approval regimes, situational ethics recognises the importance of moral deliberation throughout the ethics process (Edwards and Mauthner 2012: 20). This approach is gaining attention, most recently in UK *Concordat to Support Research Integrity* (2012), and may be of particular use to social media researchers. This potential has been most beautifully articulated in the Association of Internet Researchers' revised guidelines (2012) which offer a worked through set of principles – human dignity, autonomy,

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<sup>3</sup> With huge thanks to the PhD researchers who shared their experiences so generously and openly. With permission of all the researchers, their names are included here alongside their contributions. For more information on individual projects please see <http://dtc.webscience.ecs.soton.ac.uk/people-and-partners/list-of-students/>

<sup>4</sup> Social Media Data for Social Research (SMD4SR), commissioned as part of ESRC Big Data Research Programme, Phase 3. Unpublished.

<sup>5</sup> Sometimes also referred to as 'agile ethics' (Neuhaus and Webmoor 2011) or 'open source ethics' (Berry 2004)

protection, maximisation of benefit and minimisation of harm, respect and justice – in place of bureaucratic prescriptions for ethical research practice.

Exactly how situational ethics are implemented in practice is an open question. An ESRC survey in 2015 found that 90% of researchers using social media data assembled their own combination of discipline specific guidelines with institutional requirements, peer support and personal ethics. To some extent, of course, this has continued to be the case for many researchers – and especially those doing qualitative research. Even where sophisticated ethics review processes are in operation, I suggest that the advent of new forms of digital data and the disruptions that these pose to established processes make this situation more common and extensive for researchers using these sources. However, we must not take this to mean that we can, or should, return to the practices of the 1980s and leave the question of ethical practice solely to the individual. Whilst the concept of situational ethics provides us with a sound philosophical base on which to build, the ESRC survey also showed that researchers want to engage in and learn from (more or less formally) organized communities of practice that transcend the serendipities of everyday experience.

### *The Way Forward?*

We urgently need self-reflexive examples of the challenges faced and the practices that are developed to deal with them in order to provide a shared context for the development of situational ethics when working with social media data. Anecdotal evidence suggests that as researchers we are wary of openly discussing our practices in a field where the norms of situational ethics are emergent. Furthermore, even amongst social media researchers, it is clear that the norms are dynamic. We are all learning as we go and decisions made in good faith five years ago might seem less appropriate in the light of ongoing debate and emergent awareness of the consequences of particular decisions. We must also take into account the way that the field is shaped by external actors, outside the usual research field. For example, the social media companies that own these data impose terms and conditions on use, such that what may seem ethical (for example anonymization of data) may be trumped by what is legal (where, for instance, the terms and conditions of data use state that changing content in the data harvested is not permitted). Similarly, when working with data sets that cross national boundaries and/or in collaboration with multiple stakeholders – different owners and users of data – complex questions arise about the boundaries of ethics processes and the potential for conflict, or at least contradictions, between different practices. For example, where data are shared by stakeholders from different sectors – across commerce and academia for instance (something that is increasingly common in the collaborative projects favoured by many funding councils these days) – there may be very different interpretations of how the data should be treated and used. Similarly, different legal jurisdictions pose challenges for international teams, international data archives and research ethics governance (Wilson et al 2016).

Beyond this, it is also clear that we need to promote more interdisciplinary dialogue. Whatever the intention of bureaucratised ethics review processes, there may be a degree of local interpretation:



*Just recently my PhD cohort were discussing ethics issues on Facebook and I asked at what point the observation of publicly available data became an ethics-bounded issue. Suffice it to say there was no clear ...consensus - between doing nothing without first seeking approval or that it didn't matter at all ... I suspect the range of opinion divided along disciplinary background. **Mark Anderson***

*Having observed differences between Faculties at Southampton, and conversations with others at different institutions, there is no concurrence on what constitutes ethical online research. I feel this is one of the main factors that could be slowing progress of qualitative online research in particular. **Becki Nash***

*Currently there seems to be very little interdisciplinary thinking when it comes to the formal ethical processes. I suspect future challenges and opportunities include developing a greater appreciation of why different disciplines tend to prioritise different ethical issues e.g. personal data, anonymity, safety, and so on. **Ian Brown***

Our PhD researchers' experience suggests that these differences undermine the credibility of research ethics review processes and the practicality of interdisciplinary research. Assuming that we are going to continue with some kind of systematic ethics process, it is essential that this is seen to operate with consistency and fairness. This will need to step back from formulaic questions that assume particular norms towards more philosophical questions that recognise the unknown and require reflection and recognise the contingency of solutions. Without this we may be encouraging poor practice and risk reducing the quality of research

Notwithstanding the frustrations described earlier in the paper, we should look to ethics committees as sources of informed guidance: a much needed resource in this changing landscape. There is certainly evidence to suggest that there is commitment to this

*To be honest [the experience of applying for ethical approval was] not as bad I had been led to expect. The ethics board have in recent years become more aware and comfortable with online research methods, thanks in large part to the doctoral students and Web Science researchers who have proven the breadth and usefulness of these methods. The board were not only understanding but supportive and enthusiastic in their responses to my proposed methods. **Elzabi Rimmington.***

Changing cultural, social and economic processes are changing the ethics regime and, I am sure, will change the artefacts, workflows and hierarchies of decision making in bureaucratised ethics processes. This support will be particularly important as we move from a position where ethical practice is determined in advance, where we know what is ethical upfront (or we think we do) to a situation where the ethics are more emergent, and just as importantly where an increasing focus for ethical practice is in data stewardship, that is: how we ensure ethical practice with data that does not have consent and is not anonymised, rather than making these pre-requisites for data collection.

Finally, a point about the wider politics of data: looking at our own internal practices as social science researchers is important but we need to situate this on a wider landscape. For all that we agonise about how we should practice, others beyond the academy – in government, journalism or commercial organizations, for instance – may be less hesitant about using social media data, not least because they are not subject to the same ethics review processes. It is important that we pay attention to this for at least two reasons. First, it may be these uses of social media that

provoke the highest levels of public concern, with the potential to start a backlash that will affect all of us who see value in these data. Think, for instance of the public outcry at the infamous Facebook emotion experiment<sup>6</sup> or the Cupid ‘bad’ dating experiment<sup>7</sup>. Second, if academic social media research falls (even further) behind its counterparts elsewhere in terms of methodological and analytical expertise in working with social media data, we will be less well placed to interrogate the claims made by others from these data or to counter these with alternatives. This is absolutely not to say that we should join the ‘gold rush’ without appropriate ethical governance, and I recognise that this takes time, but it is to say that we need to push forward and think creatively beyond the established ethics review bureaucracies and discourses that, after all, were shaped on a different data landscape. Not least, what can be known and by whom will be shaped by data practices and the ethical regimes that shape them. In a climate where public concern about privacy and data ownership is rising, the importance and indeed credibility of ethical practice may also be rising and our attention to these details may put academic researchers in a position to make powerful contributions to public policy and debate and that is a responsibility, perhaps an ethical responsibility, that we should take very seriously.

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Jernigan and Mistree 2009<sup>1</sup> <http://firstmonday.org/article/view/2611/2302> Accessed 17/10/16

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<sup>6</sup> <https://www.theguardian.com/technology/2014/jun/30/facebook-emotion-study-breached-ethical-guidelines-researchers-say> Accessed 16/12/16

<sup>7</sup> <http://www.bbc.co.uk/news/technology-28542642> Accessed 16/12/16

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