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## EDITORIAL

### **Censorship in the name of ethics: Critical public health research in the age of human subjects regulation**

Confirm that all the research meets the ethical guidelines, including adherence to the legal requirements of the study country (manuscript submission system, *Critical Public Health*).

#### **Introduction**

Today, all authors who submit a manuscript to *Critical Public Health* must confirm that their research meets certain ethical guidelines and legal requirements. The journal is certainly not alone in requiring this confirmation. Identical statements—or slight variations thereof—can be found in the submission process of countless academic journals. In fact, the question has become so commonplace most of us barely register it. Taken at face value, the requested confirmation makes sense; journal editors naturally want to ensure they publish ethical research. But what does this actually have to do with ‘meeting ethical guidelines’ and ‘legal requirements’? After all, what is ethical and what is legal are not always congruent. Moreover, numerous observers assert a difference (a radical disjuncture, even) between ‘procedural’ ethics and ‘real’ ethics on the ground.

The importation of this question into journal submission processes can be traced to the Committee on Publication Ethics (hereafter ‘COPE’). Formed in 1997, the committee initially consisted of a small group of UK medical journal editors, although it now boasts over 9000 members worldwide from all academic fields. In some cases, journal editors actively joined the committee; in others, large publishing houses (including Taylor and Francis, the publisher of *Critical Public Health*) signed up their journals for COPE membership. Such membership requires that editors meet various international standards around editorial independence, confidentiality, conflicts of interest, suspicions of misconduct, and so on. For those who publish research involving humans, additional standards are required around ensuring ‘ethical oversight, appropriate consent procedures, and adherence to relevant laws’, with editors counselled to be ‘vigilant’ in this area (Kleinert and Wager 2011, 325).

In many respects, the COPE requirements replicate a scenario we have seen play out time and again in the history of human subjects regulation, wherein frameworks developed to deal specifically with medical studies are transposed to *all* research—and then implemented wholesale via administrative fiat (Shweder 2006; Schrag 2010). In this editorial we consider the implications of this expansion of human subjects regulation and its growing enmeshment with other forms of research governance. Although this is rather well trodden ground, we appear to be in the midst of an important historical moment in which critiques of the prevailing regimes have borne some fruit. We therefore hope that this editorial will generate further discussion about the distinctive issues that social

scientists working in the area of critical public health grapple with in the context of institutional ethics review, which have not been adequately highlighted to date.

### **The critiques and the responses**

Institutional ethics review processes are today an indelible feature of academic life in many Western countries (especially Anglophone ones) and increasingly beyond them, particularly in nations of the Global South that are sites of transnational biomedical research projects and public health interventions. However, the proliferation of such regimes since the 1990s has not gone unchallenged. Despite important differences between the systems in place across national settings, the criticisms are strikingly similar. As they are by now well known, we won't dwell on them here, except to say that most observers have highlighted the biomedical orientation of institutional ethics review processes and their poor fit with the epistemologies and methodologies of much social science research (Schrug 2010; van den Hoonaard 2011). Others focus on the bureaucratic features of such regimes, and their tendency for rule breeding and proliferation (Haggerty 2004), and situate the rise of research ethics oversight within the emergence of an 'audit culture' preoccupied with auditable paper trails and other empty rituals of verification (Strathern 2000).

Responses to the critiques amongst social scientists have been mixed. Some suggest that the criticisms are based on a tendency to tar all committees with the same brush, regardless of their institutional or national jurisdiction (e.g., Hedgecoe 2008). In such accounts, the ethics review process is presented as reasonably benign—or at least open to a kind of bottom-up education from researchers about what constitutes appropriate review (for qualitative research, for example). Others speak of a 'social science victim narrative' (Stark 2007, 785), and argue that the victimization of social scientists in the review process is more imagined than real. Thus, depending on one's perspective, the horror stories that circulate about some of the more egregious examples of regulatory excess are either a symptom of endemic problems, or represent exceptions that come to take on the aura of facts through repeated, uncritical citation.

Although the extent of the problems continue to be debated, the last few years have witnessed a growing institutional awareness that change is indeed necessary. For example, in December 2010, Canada's Interagency Panel on Research Ethics released revised national human ethics research guidelines that aimed to be more social science 'friendly'. Similarly, the US Office of Human Research Protections is currently toying with the possibility of sweeping changes to its national regulations. The proposed framework specifically highlights the over-regulation of social and behavioural research and the 'unwarranted variability across institutions... in how the requirements are interpreted and implemented' (DHHS 2011, 44513). Under the proposed regulations, many types of social science and behavioural research with 'competent adults' would be exempt from review.

However, somewhat ironically, just as those tasked with oversight have started to talk of scaling back research ethics regimes (or at least reining in their scope), elsewhere we see movement in entirely the opposite direction. Beyond the ways requirements for ethics review have become tied up with publication (and funding), an ever-expanding array of organizations have begun to develop their own procedures around ethics review. Although their impetus is typically a desire to ensure the research needs of the populations

they serve are met, their proliferation illustrates the ways in which the existing problems have tended to produce *more* oversight and regulation rather than *less*. In many respects this speaks to the self-perpetuating aspect of audit culture, whereby its rituals of verification create the very mistrust they are designed to dispel (Strathern 2000).

### **Issues for critical public health researchers**

Much critical public health research on the everyday practices and policies of medicine and public health demands relations with scientists, clinicians working in healthcare and service delivery, and other organizations delivering community-level programs. Such relations are embedded in complex webs of institutional assemblages, including universities, hospitals and primary care clinics, public health agencies and community-based organizations. While the resultant layering of institutional ethics review processes is an inescapable feature of health and medical research more generally, it arguably poses particular issues for critical public health researchers.

First, although our subject matter is familiar to clinicians and scientists, our approaches often differ radically. While a kinesiologist board member might acknowledge her lack of expertise in reviewing an ethnographic study on Korean religious movements (or at least recognize that some kind of disciplinary translation is necessary), she is unlikely to accede the same kind of intellectual ground in an ethnographic study on healthcare providers' attitudes towards obesity. This issue is compounded by the fact that the process of research ethics regulation and management assumes the possibility of a unitary ethical framework that covers all types of research, which is itself based on the assumption that different types of research are *commensurable* (Lederman 2007a). This speaks to the larger homogenization of disciplinary approaches we are currently witnessing—a move exacerbated by the emergence of evidence-based medicine and its intellectual offspring, which assume that different types of 'evidence' can be placed into a singular knowledge hierarchy.

Second, many critical public health researchers are interested in the ways in which biomedicine, public health and health promotion may serve to inadvertently perpetuate inequities as opposed to ameliorate them. In other words, they are engaged in 'studying up' (Nader 1972). There is little doubt that social scientists conducting critical inquiry into institutions, practices and processes experience considerable difficulties during institutional ethics review, given the assumption in the prevailing bioethical framework of a powerless, fragile and vulnerable subject. As one of the respondents in Wynn's (2011, 101) survey of ethnographers' experiences of institutional ethics oversight complained: 'It would be impossible to write about injustice if one needs the permission of "perpetrators" to study its impact', yet, as we go on to detail below, this is what is often required in the name of 'informed consent', 'transparency' and 'collaboration'.

Fundamentally this is a question of power, regulation and discipline—and, in part, censorship (Butler 1998). By 'censorship', we are not referring to the larger issue of academic freedom and the ways that institutional review processes may serve to limit freedom of speech, although their constitutionality in the U.S. context has been critiqued on precisely these grounds (see Hamburger 2004). Instead, we speak of their potential to censor as a distinctive form of *discipline*. Censoring occurs on multiple levels and is

negotiated in different ways by different researchers (often depending on their seniority and experience).

### **Censoring ourselves**

As Butler (1998) suggests, censorship *precedes* the text. Prior to the review process we are already editing our proposals, considering what types of questions might be too 'hot'. In doing so, we draw on our prior experiences of institutional ethics review and the broader stories circulating amongst our colleagues about 'the system'. This is why the debates about the degree to which the horror stories reflect systemic issues miss the point. Whether or not they are representative, they nevertheless have rippling discursive effects that shape the ways we engage with the review process. Highlighting the 'auto-censorship and self-disciplining as we write our ethics applications and even frame our research projects', Wynn (2011) observes that the horror stories are '*social facts* because they circulate in a community, and in that circulation they have important social effects' (p. 110, emphasis in original).

As Bledsoe and colleagues (2007) note, ethics committees influence the focus of our studies and the language of our proposals; we self-monitor, creating compliant 'protocols' that we know are more likely to be approved. Many readers will have had direct experience of designing projects that aim to 'get around' what they think will be the likely sticking points in the review process, such as deciding to exclude certain 'vulnerable' populations (e.g., youth under the age of legal majority) because of the extra bureaucratic hurdles for studies including these groups. Such anticipated consequences may also affect the way the research itself is approached. For example, van den Hoonaard and Connolly (2006) argue that the rise in Canadian anthropology master's theses drawing exclusively on interviews is a consequence of the perceived difficulty of obtaining ethics approval for participant observation.

In some cases, a desire to avoid institutional ethics review processes altogether may shape the types of research conducted. The prioritization of text-based discourse analyses, especially amongst graduate students, may be a symptom of this (Bledsoe et al. 2007). To provide another example of such effects, in a study of Vancouver smokers' and non-smokers' interactions in the context of outdoor smoking bans, Kirsten chose to conduct *naturalistic* observation rather than *participant* observation because the former did not require institutional ethics approval. A key factor in her decision was that her university research ethics board had a stated preference that study participants be given a 24-hour 'cooling off' period between being invited to take part in research and giving their consent, and she figured it would be difficult to obtain permission for on-the-spot interviews. Again, it was the *anticipated* issues she would experience that affected her decision.

Although it's certainly possible for researchers to engage in 'principled dodging' (Bledsoe et al. 2007, 618) or to 'simulate compliance with the regulatory ideal' (Lederman 2007b, 33), as studies of social scientists' experiences of institutional ethics oversight show (e.g., Taylor and Patterson 2010; Wynn 2011), most of us do routinely submit ethics applications for our research and comply (to a greater or lesser extent) with what we have specified in them. While our reasons for doing so are complex and varied, there is a clear fear of the consequences of non-compliance—an emotion that is especially pronounced in the accounts of students.

### **Censorship through review**

For those who want to explore institutions, everyday practices, or the unintended effect of public health policies on health and wellbeing, it is often a condition that they partner with, or at the very least collaborate with, said agencies and organizations. This push for collaboration comes from several distinct directions. Under the rubric of 'knowledge translation', such collaborative research is increasingly being required by funding agencies, based on the assumption that bringing together knowledge 'makers' and knowledge 'users' will lead to more effective healthcare systems. However, it is also a product of the postmodern and postcolonial critiques of researchers' representations of marginalized communities, and the emergence of activist organizations (especially in the areas of disability, HIV/AIDS and illicit drug use) and their demand that there be 'nothing about us without us'.

This emphasis on collaboration is particularly evident in the context of research that includes aboriginal communities, with various national human research ethics guidelines (e.g., in Canada and Australia) now requiring evidence of 'community engagement' and 'collaboration'. While such guidelines clearly attempt to correct the research abuses of the past, applied in a blanket fashion, they can inadvertently serve to inhibit important critical public health research. For example, it is increasingly common to see publications where the authors have specified that they initially planned to include the views of aboriginal organizations or participants, but gave up as a result of the logistics of obtaining the various required approvals, instead choosing to focus on more accessible populations.

However, the disciplining effects of the injunction to 'be collaborative' become especially evident in research in elite institutional settings. For example, in Denielle's experience of exploring the everyday work and management practices of foreign, state-run HIV prevention trials in East Africa, the internal ethics review process she experienced within the collaborative institution focused not on the safety of human subjects (subjects who were educated clinical researchers themselves) but instead asked comments about study population size, the data management, and how the objectives would be 'measured' (questions which reflect the biomedical orientation of the review process and which do not fit well methodologically with an ethnography of medical research). In this context, the elite administrators and clinicians who were subjects of her ethnographic study were simultaneously able to censor the types of research questions asked and limit access to field sites in their administrative roles to approve and reject research proposals and subsequent publications.

### ***Censorship at publication***

Increasingly, social researchers must contend with review board requirements throughout the research process, particularly during the end stages when they are analyzing, writing up, and presenting their results. Some ethics committees may require that institutional partners approve the research results before they are published or presented publicly (for instance, the US Centers for Disease Control and Prevention). For multi-partnered research projects, this may be demanded of the social researcher multiple times. Once again, while this might make sense in certain contexts, the request to read or even veto publications as part of the review process can effectively mute critical scholarship. In such cases, publications that do not represent the institutional ethos, or those that suggest institutional

policies and practices may inadvertently contribute to poor health or local socio-economic inequities, may not be approved.

Committees and/or directors can also insist that analyses are too 'soft', asking researchers to change language and meaning, so that the resulting publications bear little resemblance to what the researcher wanted to say. The researcher must then decide how important it is to publish that data. Do they do so without permission (and can they still tick the box that the publication 'meets certain ethical guidelines and legal requirements' if they do?) or accept the institutional governance that limits potentially important findings that, if shared, could be used to improve health or social conditions? Certainly, there is anecdotal evidence from researchers doing critical public health research on politicized topics that they have been shamed, intimidated, and even warned that should they publish or present their findings, they will not be promoted, or receive tenure, and will be unable to work in those communities again.

Of course, the very act (or attempt) to censor such institutional critiques is paradoxically part of the very critique being censored. It's like the snake swallowing its own tail. Unfortunately, this type of censorship has become increasingly common in critical public health research. For example, several years ago, an organization unhappy with the ways it had been described an article published in *Critical Public Health* initiated legal proceedings against the journal and author. Ironically, the article had highlighted the organization's tendency to avoid opening up its research products to wider academic scrutiny.

### **Conclusion**

As Nader noted more than 40 years ago, we shouldn't necessarily apply the same ethics that attend to the study of marginalized communities 'to the study of institutions, organizations, bureaucracies that have a broad public impact' (1972, 305). Unfortunately, the biomedical underpinnings of prevailing research ethics frameworks mean that they are incapable of grasping the 'subjects' (in all senses of the word) that critical public health researchers pursue—this speaks in many ways to the incommensurability of epistemologies and methodologies (and their accompanying ethical conundrums) across disciplines and cartographies. Applied in a blanket fashion, there is a very real danger that institutional ethics review processes, under the guise of 'protecting human subjects', serve to protect powerful individuals, institutions and states, thereby maintaining the status quo.

Ultimately, there needs to be further discussion about the ways in which regulation in the name of 'research ethics' can serve to censor critical public health work. Obviously, this is an issue that far exceeds the topic of research ethics regulation. Other forces such as the growing instrumentalization of research, itself a product of 'managed university' (Marginson 1997), have a noticeably blunting effect on critically engaged research; the peer review process also unquestionably performs this disciplining function (Biagioli 2002). That said, we are certainly not intending to promote a free-for-all environment where researchers have the right to say whatever they want and are accountable to no one. Most of us are acutely aware of the delicate nature of our critical reflections on policies, programmes or interventions that may be well intentioned and thus we are constantly self-censoring on multiple levels. However, when such reflexive ethical practice is overlaid, constrained and undermined by the kinds of rigid procedural ethical frameworks that

currently dominate, then we need to ask ourselves whose interests the current models of institutional ethics oversight actually serve.

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