Confronting the Anti-Democrats: The Unethical Nature of Ethical Regulation in Social Science

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ABSTRACT

The system of ethical regulation erected in the biomedical sciences, for good historical reasons, has become a major threat to the social sciences and their proper role in a democratic society. This paper is not an argument against ethical conduct in research with human subjects but a challenge to the illegitimate generalization of a model of research governance based on the particular risks and challenges confronting biomedical researchers.

The Rise of Research Governance in Biomedicine

Conventional histories of the rise of research governance in biomedicine pivot on the Nuremberg Medical Trials and the code of ‘permissible medical experiments’ set out in their final judgement (Annas and Grodin 1992; Schmitt 2004; Weindling 2004). Later scholarship has questioned the integrity of some of the prosecution evidence (Hazelgrove 2002) and the application of the Code’s principles in the victors’ biomedical communities (Beecher 1959; 1966, Papworth 1967, Jones 1981, Rothman 1993). More recently, it has also become clear that the extent to which moral principles governed research prior to World War II has been understated (Halpern 2004), although there were already campaigns for greater regulatory intervention (Lederer 1995).

The years since World War II have seen an increasing elaboration of research governance. In the UK, human subjects review has mainly developed since 1991 within the specific field of health care, through the National Health Service (NHS) controlling access to staff and patients rather than research institutions controlling their employees’ projects. It is only comparatively recently, since the publication of the Economic and Social Research Council’s (ESRC) Research Ethics Framework (REF) in 2005, that British institutions have been required to have internal processes equivalent to those of Institutional Review Boards (IRB) in the US.

There is, though, no case for regulation in the social sciences comparable to that historically established in biomedical research. The risks to human subjects are not comparable and the power relationship between researcher and researched is so different as to render prior scrutiny irrelevant and inappropriate. The rise of ethical regulation in social science is driven by a demand for ceremonial conformity, which, in turn, is a vehicle for professional dominance and, increasingly, for the interests of the office-holders and bureaucracies generated to service this demand. This ‘regulatory creep’ is colonizing new groups, practices and institutions and intensifying the regulation of practices that already come under its jurisdiction (Haggerty 2004).
The Potential for Abuse

The Nuremberg Medical Trial is central to the official history of ethical regulation. But official histories are designed to supply legitimacy to contemporary actors rather than a disinterested analysis of the past (Dingwall and Strong 1985). Critics of ethical regulation are always told that it is essential to prevent similar abuses. Two points should be made. First, the relatively developed regulatory environment of 1930s Germany did not hinder the abuses chronicled at Nuremberg (Morin 1998). Second, this cheapens the historical uniqueness of the Nazi medical experiments in the same way as the constant invocation of the Holocaust in relation to every contemporary act of genocide.

A few minutes with Google gives much detail on the Nazi medical experiments. They underline the capacity of the biomedical sciences to harm those who take part. Death or serious disability is always in the background, as at Northwick Park¹ this summer. They also exemplify the potential power of biomedical scientists in clinical or experimental situations through defining and controlling the situation in ways that constrain the possibilities of exit.

Social scientists cannot, however, harm human subjects in any comparable way. We have no research technique that carries an inherent risk of immediate death or serious physical damage. We have no power to impose ourselves on people. Social scientists are guests in other people’s lives – if anything, the power lies with our informants who oblige us to behave with circumspection in exchange for the privilege of accessing information that they control (Murphy and Dingwall in press). Given the risks of biomedical investigations, and the relationships of power and dependence in which they are embedded, it is entirely reasonable that investigators should not be judge and jury in their own cause, that someone should look over their shoulder and check that participants are not being exposed to dangerous substances or techniques and that they are not being oppressed. In the social sciences, only some psychological experimentation may require the same review. We may also identify some groups whose status to withhold co-operation from researchers is compromised and who might qualify for protection, although it is hard to see who they might be. Children, people with learning disabilities, elderly people and people with mental health problems rarely have such limited capacity as not to be able to decide for themselves whether or not to co-operate with research. Ethical review may even compromise their autonomy (Edwards et al. 2004).

At no point are we going to forcibly inject dependent patients with irreversibly toxic green stuff. Why are we treated as if we were going to?

Why Governance?

Halpern (2004) describes the way in which the growth of governance is associated with wider cultural shifts within the US since the early 1960s, which led to a declining sense of community obligation and an assertion of autonomous individual rights. Traditional systems of social control in medical research lost their legitimacy in this environment (Freidson 1970). However, the development of codes and enforcement processes reflects the outcome of political struggles for advantage (Heimer et al. 2005). These contests are not yet well-documented but include the desire of hospital

¹ Six healthy individuals who were part of a drug trial run by Paraxel to test an anti-inflammatory drug, called TGN1412, manufactured by TeGenero, fell ill with multiple organ failure after being administered the drug.
managements to lay off litigation risks, of physicians to sustain their professional dominance, and of lawyers to develop new markets.

In identifying the issue of legitimacy, Halpern signals a way of understanding the rise of ethical governance in terms other than the simplistic enlightenment narrative of bioethics. Her work is part of a tradition of institutional analysis that examines how organizations are structured by interests rather than values, as they compete for resources in a changing environment. Organizational legitimacy refers to the degree of cultural support that can be derived from the organization’s environment. However, that environment is neither static nor homogenous, with other organizations both competing for the symbolic and material resources associated with legitimacy and competing to supply those resources in return for the alliance of others to their particular projects (Scott 1991). Bioethics, for example, may both supply legitimacy to an organization and derive resources – jobs, grants, influence on policy, etc. – from that association.

In determining their strategy for acquiring legitimacy, organizations converge on the forms of the most successful entities in their market. Three processes drive this movement towards isomorphism: coercive; mimetic; and normative. Isomorphism is unrelated to efficiency or effectiveness, but is critical to the perceptions of the organization as reasonable, rational, competent, ethical, etc. However, those perceptions may be more important than the organization’s actual economic performance in securing the necessary flow of material and symbolic resources, especially in the public sector where performance is hard to define and measure (DiMaggio and Powell 1991).

The remorseless spread of ethical governance is essentially isomorphic as organizations copy fashions set by market leaders, who, in turn, cement their advantages by circumscribing others. Consider the ESRC’s Research Ethics Framework (2005) (www.esrc.ac.uk). It has no justification from a change in the risks of social science research. We have not suddenly developed new techniques that can kill people. The ESRC’s case can be found at 4.1.2.1 and 4.1.2.3.1. Their argument is essentially that everyone else is doing this sort of thing, so ESRC needs to do it as well or it will not be treated as legitimate. The first item, the spread of interdisciplinary and transdisciplinary research, is normative isomorphism, claiming professional dominance in shared projects; the second, third and fourth are mainly mimetic and the last two are coercive. In the process of mimicking other organizations, of course, ESRC is also supplying legitimacy to them, as much as deriving it. If ESRC copies the Department of Health, the Department’s Research Governance Framework becomes more acceptable and the opportunities to resist it become more constrained. The need for regulation goes unquestioned. There is no suggestion that ESRC might open a debate about the relevance of this approach in the social sciences.

ESRC are, of course, doubly unlucky in this respect because, as so often happens, they have come late to the bandwagon. Ethical governance has run into serious opposition elsewhere. Even in the UK, the Central Office for Research Ethics Committees (COREC) (2006) has been seeking to roll back NHS oversight of health services research so that its committees can concentrate on their international legal obligations in relation to clinical trials. Some of the strongest opposition to this is coming from governance committees and their officers, who are simultaneously complaining of overload and reluctant to cede any jurisdiction. In a way, we should not be surprised by such expressions of self-interest in the guise of high principle, but
it adds weight to Haggerty’s (2004) comment that once a structure has been created, it will inevitably seek to expand its jurisdiction and to increase its access to resources.

To see the sources of resistance, however, we need to look across the Atlantic. The US, the home of ethical governance, is also the centre of the emerging challenge to its overreach.

The Worms Turn

In his essay on the relationship between the social sciences and their rivals in the field of commentary on contemporary social life, Phil Strong (1983) explores the tensions that arise where both parties use similar methods of inquiry in different institutional contexts. Is sociology ‘slow journalism’ or journalism, ‘instant sociology’? What are the costs of sociology’s concern for rigour, system, cumulation and precision in the marketplace for ideas? In this case, what are the costs of regulating the same enterprise in different ways, particularly when the result is to handicap those elements that would generally be thought of as most disinterested, reflexive, unconstrained by partisan passions, etc.? Take covert research. Journalists like Barbara Ehrenreich (2001; 2005) and Polly Toynbee (2003) engage in it, write books that sell in large numbers, and generate great public excitement about the findings. Ehrenreich’s recent books, Nickel and Dimed and Bait and Switch, both made the New York Times Bestsellers list. However, Ehrenreich faked CVs and references in both cases, to conceal her identity as a journalist and social investigator. The books are widely assigned to US sociology undergraduates and held up as examples of the sort of thing that sociologists ought to do – but neither would pass an IRB or an ESRC-compliant REF committee because of the lack of consent among the parties documented in them, although most names and identifying details have been changed.

As Haggerty (2004) points out, deception has become a staple not only of journalism but also of entertainment. It is also increasingly important in law enforcement, where the line between surveillance and entrapment is ever more finely drawn. It is unsurprising that we increasingly question the fairness of restricting serious academic inquiry, while tolerating reality TV, hoax shows and ever-more intrusive security work.

Governance as Censorship

The parallel with journalism is important because of the place of the First Amendment in US political culture. This is the entrenched provision that bars Congress from making laws that would abridge either the freedom of speech or the freedom of the press. Both are seen as such fundamental values that no transient politician should be allowed to compromise them. In a recent paper, Philip Hamburger (2005), a law professor at Columbia University, has argued that the US IRB system breaches this Amendment. Research is, in a legal sense, a form of speech and research publication is covered by the definition of ‘the press’. IRB review represents a form of licensing of speech or of the press. It is, in effect, a censorship of ideas, so that only those approved by the prior scrutiny of government agents may enter the public domain. If censorship of the press is unlawful in the US, then so is censorship of researchers.

The UK does not have such a robust approach to freedom of speech and the press. The European Convention on Human Rights has a much more qualified approach, and it would be more difficult to argue against government censorship on constitutional grounds. However, it is worth considering why the authors of the US constitution felt
that this was such an important principle. The First Amendment formed part of the Bill of Rights sponsored by Jefferson and the Anti-Federalists, who were seeking to prevent the creation of a dominant central state power in the new nation. Free inquiry and free dissemination of the results through a public realm accessible to all citizens were fundamental checks on authoritarian government and its abuses. Of course, there were, and still are, many issues about whose voices are heard in the public realm and about whose interests and inquiries are supported. Nevertheless, the underlying principle is of the greatest importance: the abridgement of free speech, free commentary and free inquiry is a step on the road to tyranny.

**Fetishizing Consent**

Where does this leave research participants? If the censorship being erected in the UK is antithetical to the basic principles of liberal democracies, are informants to go unprotected? Do they not have rights to consent? The European Convention on Human Rights (ECHR) seems to endorse this constraint, particularly in stating that free speech may be constrained *for the protection of the reputation or the rights of others*. But this, of course, begs the questions of whose reputation and whose rights? Democracy is also about the mutual accountability of citizens to each other, which requires openness to proper inquiries about the justification of the reputation or the entitlement to rights. Medical sociologists should be among the first to recognize this because of its centrality to Talcott Parsons’s (1952) account of the sick role. Parsons’s great insight was that illness and medicine had to be understood within the sociology of deviance. Parsons saw that illness was the term that we happened to use to describe unmotivated deviance. The distinction between motivated and unmotivated deviance was a critical solution to the maintenance of order in modern societies. Motivated deviance – crime – elicited a coercive response, which isolated offenders and provided for correctional treatment. Unmotivated deviance – sickness - elicited a supportive response, where the resources of the community might be deployed for the temporary sustenance of the deviant. Medicine was the control agency charged with adjudicating on the validity of the claims for support and guiding the sick person back to a productive role within society. The sick role revolves around an inherent conflict between the well and the sick: how can the well be sure that their support will not be abused? How can the well avoid being asked to write blank cheques for the care of the sick?

This links to another ethical debate: what makes taxation legitimate? This rests on democratic assent. If this assent is to be adequately informed, however, there must be evidence that tax revenues are being spent efficiently and effectively, and probably equitably and humanely. If tax is raised simply to support the pet projects of legislators without regard to those questions, it is intrinsically unethical, extortion rather than taxation (von Mises 1996). Both the administrators and the recipients of benefits from taxation have an obligation to participate in properly conducted inquiries to demonstrate to taxpayers that their funds are being disbursed in ways that achieve the intended goals. Patients may be properly required to participate in research to establish that they are appropriate tenants of the sick role, that support to them is proportionate to their need and that they are complying with the prescriptions for limiting that claim for support, whether by seeking recovery or maximizing their fitness to contribute productively. Similarly, physicians, and other health system personnel, may be required to co-operate with properly conducted research to determine whether their claims on the taxpayer are proportionate to their conduct of
their adjudication on claims to the sick role and their therapeutic efforts to discharge claimants from that role. The same principles apply to insurance-funded health care, where the balance is between those who are paying into the pool and those who are drawing from it, whether as administrators or physicians, or as patients. With very few exceptions in the modern world, the sick depend on other people’s money and goodwill and are a particularly condign case of the mutual accountability of citizens.

Two further comments need to be made here. One is to clarify the concept of ‘properly conducted research’. By this, I am thinking of research that is done in a technically competent fashion. I do not, however, want to replace the REF by a mandated process of technical peer review for every project that every social scientist might want to do, whether or not it requires external funding. This simply substitutes one illiberal process for another. If we believe a free society requires free researchers as much as free journalists, then all prior licensing regimes are barriers to innovation and free communication of ideas.

The second is to address the issue of consent. John Harris (2005) has argued that there may be a positive moral duty for us all to participate in biomedical research, since we all benefit from it. This should not be subcontracted to the poor and economically vulnerable who respond to the financial incentives used to recruit most biomedical research subjects. There are many circumstances in which communities may compel people to contribute to public goods: this may be one of them. My argument is similar, in the sense that the obligation to participate in social science research may be one of mutuality, of allowing one’s behaviour to be audited in the interests of other community members who are funding it or need information to determine whether to trust the claims that one is making. This applies to everyone, because we all derive benefits from our participation in that moral community. However, I place less weight than Harris on the issue of compulsion. We must not fetishize informed consent – but we can approach this as a pragmatic rather than as a principled matter. As a question of good research practice, and the self-interest of the professional researcher, we should seek to obtain consent wherever this is reasonably possible. This is, however, a dynamic process, not a form designed solely to manage litigation risk. It involves the construction of a customized relationship between researcher and researched, where the researched are offered explanations tailored to their level of understanding and concerns, not presented with legalistic formulae that require an advanced education to be intelligible. Social scientists are not homeland security personnel. We cannot force our informants to provide information. We depend on their co-operation and goodwill – but these ends are not served by the ESRC’s demand for written evidence of a contract of consent. Contracts are designed to manage adversarial relationships. We cannot function in conflict with our informants.

What is to be done?

It is easier to point to the flaws in the present systems of ethical governance than to lever their destruction. Clearly some of the enthusiasm with which COREC has addressed the task of reforming the NHS system comes from the frustration of NHS planners, managers and policymakers with finding access to crucial information being obstructed by a system of their own making. However, that is not, in itself, enough to topple an edifice that depends on its own weasel vocabulary of motherhood and apple pie. Surely only the corrupt among us have anything to fear from a review? There is, however, now abundant evidence that the corrupt have little to fear, while honest and
conscientious scholars, seeking to engage in research intended to enrich the public realm, are subject to pettifogging obstacles, designed to bolster the power of the organizations charged with governance. The more processes can be extended and elaborated, the more resources these organizations can command and the more power accrues to their personnel to determine what scholars are, and are not, allowed to think and say – and to determine what passes into the public fora of debate and democratic deliberation. Only a saint would resist the corruptions that flow from this power – and we do not live in a world of saints.

If we apply neo-institutionalist thought, however, we can see points of vulnerability. We need to deprive these bodies of the oxygen of legitimacy. This creeping tyranny feeds on our reasonableness. We must stop colluding and call it by its proper name, a process of censorship that is disabling to the democratic values by which we seek to live. Ethical governance and professional ethics should not be confused. Ethical governance is about censorship and the exercise of power. Whatever the motives for which it is advanced, it is profoundly anti-democratic. Professional ethics is about respect for our common humanity and the mutual obligations that this creates. It is about integrity and virtue in our scholarship. Those are real values, values of liberty that always challenge those who dislike democracy and prefer to sustain a world where their views and assumptions will go unexamined and unquestioned.

References


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