

Ethics Committees and IRBs: Boon, or Bane, or More Research Needed?

Ross Anderson

University of Cambridge Computer Laboratory
JJ Thomson Avenue
Cambridge CB3 0FD
United Kingdom
`ross.anderson@cl.cam.ac.uk`

Abstract. A summary of remarks of the keynote talk.

Institutional review boards in the USA, and ethics committees in the UK, have their roots in medical research. In the US Tuskegee scandal, black patients with syphilis were left untreated even after an effective treatment became available in the form of penicillin; in the UK Alder Hey scandal, pathologists retained body parts from deceased children without informing their parents. Yet simply having a committee of doctors review other doctors' research proposals isn't foolproof, as it disregards the differing perspectives and cultural assumptions between doctors and patients. For example, ethics committees were already well established in Britain by the time of Alder Hey, and it's not entirely obvious that a committee of half a dozen randomly-chosen white doctors in the deep south in the 1940s would have acted any differently from the Tuskegee team.

The current tussle in the UK is between a medical research establishment that wants access without consent to medical records that have been "pseudo anonymised" in that the patients' names and addresses have been removed, and a privacy community which points out that most such records can be re-identified easily. Computer scientists know that anonymity is hard, thanks to the work of Denning, Sweeney, Dwork and others; this knowledge is slowly percolating through to the policy community via Ohm's work. Yet we have already had an incident where over eight million "pseudo anonymised" records were lost when a researcher's laptop was stolen; should such a haul end up on wikileaks or paste-bin, we might have a scandal like Alder Hey that could damage public confidence in medical research. Could such a dilemma be fixed by ethics committee?

Here is a second example. One UK university has data on the movements of millions of vehicles taken from automatic number-plate recognition cameras. This has been "pseudo-anonymised" by hashing the license plate numbers, yet someone who knew that a target drove on road X at time t could search for all other sightings of that vehicle. Yet the Department for Transport asserts this is no longer personal data. It follows that anyone should be able to obtain a copy using the Freedom of Information Act — and by that I mean anyone, not just any researcher working within the framework of an ethics committee. The

comfort that the committee's existence gave to civil servants may have placed the data in a position from which it could escape control altogether.

It may be said that ethics committees give comfort to researchers who work in the many legal grey areas. An example raised by David Erdős of Oxford is that data protection law can easily be interpreted as prohibiting social science research on living individuals where their consent cannot be obtained, a topic case being when you send off job applications to hundreds of professors in order to assess whether there's any racial or gender bias in their hiring practices for postdocs. In fact, a cautious interpretation of the law would prevent even a book review — criticism of the writing of a living author is personal information about him, made available without his consent and with the potential to do real harm. This highlights the wildly different interpretations put on the law by different institutions. At Oxford, ethics committees are starting to give social scientists a hard time over research which the scientists claim is obviously justified; a Cambridge ethics committee chair said that “an academic who asked for ethics clearance to write a book review would be told to go away and stop being annoying”.

The diversity causes real friction. My team planned to do some work with another university on how best to tell people that their PC has been recruited to a botnet, so as to persuade them to clean up the machine without causing undue alarm or distress. This is an important problem, as some 5% of PCs worldwide are infected at any one time. But our research project has been stalled. Ethics approval at our end is done at a departmental level and is straightforward; at the other end it goes to a university-wide committee that has “levelled up” to the much more heavyweight procedures expected by researchers in psychology and medicine.

Yet ethics committees don't do much heavy lifting when we face real problems. Colleagues and I do research into payment systems; fraud victims come to us after being fobbed off by their banks or credit card issues, and we often figure out a new *modus operandi*. In order to test it, we often have to do experiments on live systems. How do we ensure that we don't get arrested for conspiracy to defraud? The answer is: by taking money only from our own accounts; by reading the law carefully and discussing it with specialist lawyers; by telling the police's e-crime unit what were doing; and by having a policy of responsible disclosure. Even so, we've had a bankers' trade association trying to bully us into removing a student's thesis from the web when it documented a vulnerability that was already being actively exploited and which the banks preferred to cover up rather than fix. Our protection in that case came from the support of university colleagues and others who backed us when we told the bankers where to get off.

So is an institutional review board, or an ethics committee, any use at all? It may well be. It can shield an experimenter by documenting intent and thus removing the *mens rea* element from a possible offence. If there is a real issue of law and policy then the experimenter really has to square up to it; but such issues aren't always visible in advance. The boundaries of the law are fuzzy and context-dependent; and context can change overnight. After 9/11, jokes about

terrorism were not so funny for everyone, and attitudes to matters like race and sexuality also change, though at a slower pace.

So how can we maximise the benefit from ethical review, while minimising the harm? It appears that almost all of the benefit from ethical review comes from its very existence, while the harm escalates once it starts to be elaborated into an intricate bureaucratic system. And this may do harm in more ways than one, for example by moral hazard.

In order to push back on the bureaucracy, we should perhaps investigate whether researchers subject to heavyweight ethical review are more reckless than those whose institutions run ethics with a light touch.