

## **What's culture got to do with the ethical review of biomedical research ?**

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I was recently asked to speak at the 12<sup>th</sup> meeting of the Forum for Ethical Review Committees in Asia and the Western Pacific Region (FERCAP) held in Colombo in November 2012. The theme of the conference was the place of Development, Ethnicity and Culture in the quest to improve human subject protection in biomedical research. These are undoubtedly important variables in the work of ethical review. They are always there, but typically in the background, and often out of focus. Everybody knows that they are there with the potential to shape what is going on but, in practice, they are very difficult to deal with. They are inherently challenging, uncomfortable and messy. In my view, FERCAP was taking an important step in trying to foreground these important dimensions of ethical review. As a social anthropologist, it seemed like a good opportunity to think a little bit more carefully about the place of culture in ethical review and below is an edited version of the talk that I gave at the opening plenary of the conference.

In the context of biomedical research and the way it is subject to ethical review, all three terms - development, ethnicity and culture – refer to aspects of connection and difference. Typically the terms operate across relationships of inequality and imbalances of power. As a social anthropologist, I am interested in all three concepts but particularly the third element, the idea of culture – why we have it, what it is and how it is expressed every day in our interactions with others.

You will not be surprised to hear that if you ask an anthropologist for a definition of culture you might be there for quite a long time - anthropologists have been arguing about what culture is for decades. In the 1950s, Kroeber and Kluckhohn identified 162 definitions. Some have argued that it is so overworked as a concept as to be of no utility whatsoever.

For the purpose of this brief exposition of culture, let me begin by saying what culture is not. We should leave behind at the outset the idea that culture is all about elitism and hierarchical distinctions – it is not about the paraphernalia that enable some people to think of themselves as cultured. (Recall Ghandi's comment when asked what he thought of Western culture – he replied that he thought it would be a good idea.)

The definitions of culture that I want to cover are threefold:

1. Culture is a universal feature of what makes us human
2. Culture is what enables collectivities of human beings to distinguish themselves from one another
3. Culture is process rather than a thing we can point to – it doesn't separate us – it connects us.

I will refer to these as first order, second order and third order, respectively.

The first order idea of culture treats it as a universal feature of the human species. This idea emerged in the nineteenth century. At this time anthropologists and philosophers began to contemplate our place in nature as a result of Darwinism and the encounter with our evolutionary past. This was also a time of huge political turmoil brought about by industrialisation and colonial expansion. At that time, the idea of the universality of culture was a politically powerful statement. At a time of widespread racial and cultural inferiorisation, it claimed that in effect all peoples of the world had the same capacity for culture - as Tylor put it in his famous definition: culture is *that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society*. This was an important claim being made for the underlying unity of the human species.

But, it was not enough to just say that we are all the same. We are all the same but in different ways. We all have culture but we express it differently – we all have knowledge, belief, art, morals etc but we have acquired them in

ways that mark us as distinct – my beliefs, values and customs are not necessarily yours – they have been acquired in a different place, under different circumstances. Crucially, these differences are mutually intelligible and translatable – my art maybe different from your art but we can, if we try hard, make sense of one another’s systems of representation and meaning – as a social anthropologist this is what engages and fascinates me – our capacity for mutual understanding. But, I am also interested in what is possibly a greater capacity; the capacity for misunderstanding and the problems that arise when the culture of one group claims to speak for another, or vice versa. As George Bernard Shaw once put it ‘the single most difficult problem with communication is the illusion that we have achieved it’.

On the FERCAP agenda were lots of magnificent examples of this second order notion of culture. In short, efforts being made to counter the tendency of one voice to speak for another. Into the hegemony of a Western-inspired biomedicine and ethics other ways of seeing, other traditions, other voices, and other cultures were presented. For example, there were presentations on Ayurveda, Chinese Traditional Medicine and other healing systems. These come with different epistemologies and point to different readings of the body and how it might be acted on by the healer. There were also other traditions of ethics and values offering different possibilities for human flourishing. These could be seen in presentations on Confucianism and Buddhism to name but two. Scientific judgements are clearly fundamental to ethical review, but there was a suggestion that science itself lands in and is shaped by these different cultural contexts. The conference provided some important steps into how these traditions interface with science and how diversity might be brought into the equation.

The third order reading of culture is one which in some respects links back to the first. It sees us all ‘doing’ culture as practice and process in everything we do. We receive systems (language, beliefs, ideas of who and what we are as persons and as material bodies). We are also able to modify, combine, and extend these systems with extraordinary fluidity and creativity. In this view of culture, we are in a perpetual quest for order and meaning and, moreover,

trying to persuade others of the correctness, of our own ways of doing things. (unless, that is, we happen to agree with them). In this sense, culture is essentially about connection across difference; it is a meeting point, a point of expression and engagement.

All this may seem a long way from ethical review but it is my contention that ethical review committees (ERCs) occupy a critical position in relation to these three orders of culture. First they are charged with responsibility for protecting the 'human' in biomedical research; that sameness that resides beneath all our differences. Second, they are charged with taking manifest cultural difference into cognisance in the conduct of biomedical research – to ensure that one culture doesn't speak for or otherwise obscure or erase another. Third, the form that ethical review itself takes is a cultural form. Culture is not external to the work of ERCs but is expressed in the work that they do and how they do it. Considering each of these readings of culture illuminates a different set of tensions and challenges for ERCs to engage with in their practice. Let me try to give an example of each:

1. What is the 'human' that ERCs strive to protect? ..... I would say it is a construct that has emerged out of an essentially Judaeo-Christian tradition. It has culminated in a mostly secular and legalistic notion of the autonomous, rights bearing subject. This idea of the subject features in legal and human rights discourses and has passed into consent practices in transnational biomedical research. In essence, if we strip away relationships, power structures, and context we will find at the core the individual, the agent, the self, the person, who can make decisions and give consent so that others may act upon their bodies, and perhaps their minds. To do otherwise would give the appearance of using humans as means to an end rather than treating them as ends in themselves. But arguably, what is being stripped away here is culture, the very things that give a person their sense of meaning, order and place in the world. A critical reading of this process might question the particular reduction of all to one, pointing

out that the residue that we are left with might itself be a cultural artefact of the second order and not the first order.

For example, in research carried out over a number of years into ethical capacity building in Sri Lanka, a recurrent theme has been a sense of unease about the deployment of the notion of autonomy among local practitioners. It is felt by many to be a foreign import that doesn't quite sit comfortably with a gut sense of how relationships should be with patients in ones role as a doctor and a healer and indeed, as a researcher. One response that this line of argument might provoke is that we are simply raising a cultural smoke-screen behind which lurks medical paternalism, vested interests and exploitation of the vulnerable. This may indeed be the case. But, another response might be that, notwithstanding these concerns, there is a kind of erasure going on here, the effect of which is to bring local values into conformity with global systems and standards.

2. The second example concerns what I am going to call the cultural imagination and what is perhaps a profoundly humanistic function in the work of ethical review. ERCs are there to evaluate risks and harms that might arise in experiments involving human subjects. The starting point for any application is a research protocol. The style of the protocol is invariably technical and constructed in such a way that researchers and 'subjects' are described impersonally and with maximum detachment – socially and culturally these documents are intentionally factual and flat. Through ethical review, there is an opportunity, indeed an expectation, for the cultural imagination of the reviewers to be brought into play. It is the task of the ethics committee to animate the protocol (to bring it to life), that is, to try to imagine the people who are to be approached and the worlds in which they live. Arguably, this is why lay people and even, on occasion, social scientists, are brought on to ERCs. Their expertise is of a different kind (which, incidentally, brings a rather different clash of cultures). It is there to help stimulate acts of the imagination that will bridge the

universe of the scientist and the multi-verse in which people actually live. It is in this world and not that of the scientist that they will be making sense of the acts of experimentation they are confronted with. What is it like to engage with autonomy and informed consent in a setting where heteronomy or distributed decision-making is a primary facet of culture? What is involved in imagining this transaction against a backdrop of poor literacy and chronic poverty?

3. The third example, concerns ERCs themselves. We are all familiar with the genealogy of ethical review – Nuremburg, Helsinki, Belmont. Out of this genealogy ethical review has evolved and replicated, rather like DNA; diffusing across the USA, Europe and the globe to produce standardised procedures for ‘ethical review’. These are the tools of choice when it comes to evaluating risks and harms in the face of potential abuse. Yet, the work of ERCs is carried out within different political, economic and moral regimes. To take the genetic analogy further, the genotype results in very different phenotypes when it is expressed in different environments. Considering these variations throws into relief different bureaucratic and legal cultures; different ways of managing power and decision-making. It also exposes particular ethical and moral sensitivities. Conversations around these sensitivities are ones that FERCAP has been particularly effective at facilitating. Given that ERCs are quasi-legal bodies that operate at the edges of government control, these conversations open up the possibility of wider debates. Debates about different kinds of authority - scientific, cultural and ethical – and how these relate to one another.

From research I have carried out into the regulation of human experimentation in Asia over the last decade it is clear that these questions regularly exercise ERC members when they reflect on their practice. Beneath the documentary and procedural claims to objectivity, measurement and disinterested evaluation, there is a far more complex landscape of negotiation, discretion and situated concerns about the scope, authority and legitimacy of ERCs. I would

contend that this is the cultural work of ERCs which involves a lot of persuasion, that is, rhetorical work that is rarely open to scrutiny. Crucially, this work enables ERCs to appear in their form and function just like ERCs anywhere else in the world.

Underpinning each of these readings of the work of culture in ethical review is a deep-seated tension. It is one that I want to bring to the surface by way of conclusion.

At the heart of the globalisation project is the work that goes into standardisation, universalization, harmonisation, and all of those things which tick away behind the scenes making things appear the same the world over – Coca-Cola, airport check-ins, protocols for IVF treatment, HIV campaigns, clinical trials, and ethics committees to name but a few. Without this work, global projects in the form that they now exist would falter and fail. The case in point here is global biomedical research. Without the work of harmonisation, ‘experiments’ would not travel and, to a large extent, it is the fact that they do which is why FERCAP is interested in the notion of culture.

In a sense, the conference was trying to recognise something that is apt to become lost in the pull towards standardisation and that is the things which, despite their thoroughgoing relevance to researchers and subjects alike, are in the background and tend to pull in the other direction (see the figure below). These are things that, from the standpoint of living diversity, challenge universalist presumptions and particularly where such presumptions obscure other versions of how the world might be. So, in the midst of the powerful economic and political pull of guidelines, protocols, standard operating procedures, standardised consent forms and so forth the conference attempted to draw attention to points of friction, resistance and non-conformity within the prevailing direction of travel. ERCs lie at the heart of this tension and have a huge and difficult responsibility to discharge.

The conundrum that is faced by those who are working to improve the effectiveness of ethical review, however, is how to do this without damaging

the very things which are important to the people they are trying to protect.  
How to represent diversity in the midst of standardisation?

