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What's Law Got to do With Good Science? A Right to Science, Good Regulation of Science and the Politics of Animal Research, For Example

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It was an honour to read the incisive critiques of and generous engagements with *Good Science* contained in this *Debate and Dialogue* section. The pieces by Thérèse Murphy, Ilke Turkmendag and Marie Fox each identify areas where more attention to the law would strengthen and expand the work, and each has opened up new research questions for me. All are pioneering scholars of the terrain where law and society and science and technology studies (STS) productively enrich one another. I was previously familiar with their work and am now much enjoying reading their work more systematically; their commentaries are deeply informed in each case by their own scholarship. In her critique, Thérèse Murphy asks what role rights play in adjudicating and innovating in sciences that, like stem cell research, have ethics, and questions *Good Science*'s relative absence of engagement with human rights. Ilke Turkmendag applies to the UK mitochondrial DNA case my argument about California stem cell research that when biomedical cures are seen as paramount, other vital moral perspectives get shut out. She argues that good regulation is essential to the legitimacy of new technologies in the United Kingdom, and thus that the absence of excluded moral perspectives within regulation has a negative effect on public trust in the sciences in question. Marie Fox pushes me on my argument for ending substitutive research subjecthood for animals, underlining how difficult such an undertaking would be, and pushes me on lines of inquiry barely begun in a too truncated chapter.

In 'To talk about science is to talk about ethics – but not about rights?' Thérèse Murphy writes:

> In reading *Good Scien*ce I was looking for resonance with rights or human rights. I found it in a range of places . . . But I had to work harder than expected, which brings me to the question I want to ask in this short reflection piece: Why was that?

Murphy speculates that my disciplinary place within STS and transnational feminisms might in part be responsible for my paying little attention to human rights. She also asks, however, if I fail according to my own explanatory criterion of drawing on 'the repertoire available in a given place (p. 259)'. Murphy (2013) asks, '(a)ren't human rights part of the repertoire in a range of places, both local and global?' I agree that disciplinary inclinations matter, but it is also important that human rights did not figure centrally in the debates we were having and that were being waged nationally at the time. The EU and the United States are different in this regard.

I grew up in a United Nations/World Health Organization family, so the links between human rights and health fundamentally shape my understanding of the post-second World War world. And yet, Murphy is right that human rights are not a central analytic frame in *Good Science*. With the help of Amazon, I discovered that I mostly used rights in the context of various kinds of minoritarian rights threatened by the status quo, as opposed to the universalist-aspiring 'human rights'. I use the expression 'disability rights' 20 times, 'animal rights' 15 times and 'minority rights' 7 times. And where I use rights in more majoritarian ways, it is to point to their use to strengthen, rather than allow citizens to petition (as human

rights can when functioning at their best), the state. Thus, I comment on the passage of California's Stem Cell Research and Cures Act that it established 'a constitutional right' 'to conduct stem cell research', and I refer to the legal background provided by property rights, a woman's right to choose and the right to reproductive privacy that were argued in US constitutional terms. The only times I talk about human rights per se are in describing our goals for a more inclusive ELSI or ELSPETH curriculum, placing human rights under the 'L' that stands for 'legal' aspects in these acronyms, and in referencing the Universal Declaration on Bioethics and Human Rights as a recent text in the evolving international background conditions for post- WWII and, more recently, post-1970s research ethics out of which oversight of US stem cell research developed.

In other words, Murphy is correct that 'rights or human rights' are present in 'a range of places', but that rights, and especially human rights, are not centred. This is true even though I have never spent more time listening to and speaking at events that featured academic lawyers than during the early years of human pluripotent stem cell research. Murphy notes that, in general, lawyers have been slow to consider science and ethics in relation to human rights. I am not an expert like her, but I would add that among academic lawyers concerned with California stem cell research at the time, the principal interest was in intellectual property and patent law (and their conditions of possibility, such as informed consent, acceptable derivation of stem cell lines, licensing and technology transfer), not human rights. As regards my own disciplinary commitments, it is true that transnational and intersectional feminisms can lead one to be very wary of human rights, on the grounds that shared humanity, and thus one's ability to access rights to common humanity to redress settler, colonial, state, masculinist, racist, or for that matter, corporate, power (or even health care itself in the United States), is not something that can be taken for granted. Race, class, gender, sexuality, citizenship, religion and disability are too often decisive; indeed, a major focus of *Good Science* is how hard it is to bring any kind of shared notion of humanity, social good or redistribution into consideration in the US biomedical innovation culture I was describing.

The main reason I didn't have much to say about human rights, however, was that they didn't come up. Those were not the terms in which the debates I was following were conducted. STS takes its methodological empiricism very seriously, and so to that extent this could be said to be related to my STS sensibilities. The procurial frame I characterised combined a moral imperative assumed to have the consent of every citizen of California to seek cures, combined with an economic innovation logic that included subsidising the precompetitive part of the R&D chain, and then in the case of proposition 71 – uniquely, perhaps – ethically and economically de-risking a considerable part of the competitive part of the bench-to-bedside innovation process, to promise regenerative (trickle down) economic activity and biomedical cures. Economic and ethical processes and language were thus empirically paramount, and my archive and ethnographic sites dictated my emphasis accordingly. Triage, the method I elaborated to examine how different lives were positioned and valued within this frame, revealed appeals to rights almost exclusively in the minoritarian sense, as a way to speak about those left out. Even then, justice, a more redistributive term, often replaced rights, as in 'disability justice' rather than 'disability rights'.

Shortly after *Good Science* was published, the so-called 'right to try' movement took off nationally and culminated in the federal 21st Century Cures Act of December 2016, 3 years after the book's publication. That Act, resolutely pro-cures in its framing, challenged the speed of the FDA regulatory process and continued the US patient activist challenge to

heretofore fundamental epistemic and regulatory building blocks of good science such as randomised, controlled trials and the funding for, sequence of, and reporting from pretreatment clinical trials. Murphy's commentary suggests that the use of the phrase 'right to try' would make an excellent research project for thinking about how ethics and rights (albeit still not human rights, I'd argue) can shed light on one another. Murphy's work on 'the right to science' would be an excellent way to approach this question.

The second piece, Ilke Turkmendag's 'Good Regulation of Science: A Matter of Rhetorics' begins by placing *Good Science* in the Jasanoff (a lawyer and pre-eminent Harvard STS scholar) co-productionist strain of STS, correctly identifying my training and my interests in the links between science and democracy, and in the differences among national social contracts for science. Turkmendag asks whether my argument about the legitimisation of US human pluripotent stem cell research through the ethical choreography of the 'procurial' frame can be applied to the British process that led to the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015. Turkmendag deftly shows that the UK debate focused on particular individuals afflicted by mitochondrial disease and the potential of MRT to alleviate that suffering, eclipsing the fact that Britain was thereby becoming the 'only jurisdiction in the world to legally permit human germline modification'. As I found for the US case, she finds that several important bioscapes, or kinds of lives and sets of concerns, are marginalised by this pro- cures framing. Furthermore, rather similar concerns were side-lined in both cases, including egg donation, inequality of access and disability justice.

Like me, Turkmendag is interested in differences. She asks about differences between 'procurement objections and concerns' 'across different types of research and reproduc- tive material', whereas I focus most of my comparative attention on the differences between political parties within national settings, and those between nations. The fasci- nating part of Turkmendag's commentary, then, from my perspective, is in how she characterises legitimacy for (reproductive) research and innovation in the United King- dom and its consequences for what 'pro-cures' implies in the two countries. Turkmendag describes the United Kingdom as a place where science is generally considered legit- imate if it is 'safe, effective, and well-regulated'. My time serving on the Nuffield Council Working Group on Genome Editing has shown me that public consultation, current limits to science, solidarity, the robustness of the HFEA (itself grounded in British scientific priority in embryology and clinical priority in reproductive technology and its ethical regulation) and coming to a sensible scientific consensus after a decent period of time are paramount, whereas in the United States, my service on ethics com- mittees has focused on compliance with rules for the provenance and procurement of biomaterials and the right treatment of putative research subjects (humans, animals, embryos). Dissent is solicited but not with the purpose of incorporating it into regulation in the United Kingdom; in the United States, dissent that matters politically is worked around and operationalised into acceptable procurement, where other kinds of dissent are ignored because they are thought to belong elsewhere. In other words, there are signif- icant differences in what public engagement and dissent in this field means and how it is handled in these two countries.

There are consequences to these differences. In the United Kingdom, Turkmendag argues, good regulation matters in securing public trust for innovation. Ethical perspec- tives that got sidelined through the overly narrow focus on individuals with disease weaken regulation and thus have an impact on public trust. To increase legitimacy, a way needs to be found for these dissenting perspectives to make their way into the resulting regulation. In the United States,

however, regulation is widely seen as standing in the way of innovation, good science and access to treatment, and federal regulations are frequently seen as restrictive, especially in reproductive, regenerative and genomic sciences. Ethics committees (and the policy documents that enact the requisite ethical choreography) become the routes through which acceptable pathways around politically salient dissent are secured and normalised. These UK/US differences do not just imply different understandings of public engagement, of ethics and of legitimacy; they stem from and in turn reinforce different meanings of substantive democracy and different solutions as to how to manage pluralism to promote ethically challenging science and its associated economic activity in these two national contexts. The contexts are both pro- cures, favouring individual biomedical treatment over social justice concerns; nonethe- less, how they get there is quite different.

The third and final commentary, Marie Fox's 'Good Science and the Politics of Animal Research', knowledgably situates my arguments about the future of animal models in good science into a broader field of animal rights scholarship and 'the animal and animality in our broader political context'. As she rightly notes, I argue that the animal model is a historical 'product of the entwined logic of both ethics and best scientific practice dictating that research be done in animals first', and so I steer clear of making the debate appear to be one of ethics versus science. My 'challenge to the animal use paradigm is grounded in the notions of good science and good regulation' and is informed by the fact that the actions of cell-based therapies and cell-free biologics do not appear to transfer straightforwardly from animal models to humans, and thus more and more transgenic and humanising efforts are necessary to keep animal models fit for purpose. It is hard to argue this is good for the animals in question and contravening trends to make in vitro and in silica models better (such as disease-in-dish models, three-dimensional bioprinting, organoids and big data) shift the cost–benefit balance away from using animals to using in vivo-ised in silica and in vitro models instead. I point out that these arguments from good science against what I call 'substitutive research sub- jecthood' also apply to moving away from long histories of using some kinds of humans to stand in for others in biomedical research.

I found in my field work around regenerative medicine, however, that decommis- sioning animals from scientific and clinical model work will take a much more concerted effort than simply switching model systems once that cost–benefit point has been reached. Epistemological and regulatory standards are deeply imbricated with animal models and a large-scale shift to different model systems that is also decom- missioning of animals will require multi-jurisdictional work, infrastructural coordination and alternate ways of characterising cell lines and documenting safety and efficacy. The cost and care required to decommission the animals themselves will not be insignificant, and, as Fox points out, the economic consequences of reducing the animal model business would also be significant. Furthermore, rhetorically, (spokes- people for) scientists and some animal rights activists are deeply committed to an oppositional view, as I illustrate with how easily the language of 'kitty killers' versus 'terrorism' was invoked at the University of California during my research for the book. Fox gives a fascinating reading of a 2014 UK Home Office plan to extend the three Rs to develop alternative model systems similar to spirit to those for which I argue that simultaneously reaffirmed the need to keep animal models going. Fox's observations lend further support to my argument about the complexity and scale of the undertaking. In *Good Science*, I called for an explicit set of benchmarks and the identification of international leadership for such an effort precisely because of how difficult this task appeared.

Although my argument is grounded in good science, I also make a 'greater moral universe' argument that is geared towards making it less daunting to begin rhetorically to decommission animals in research. The basic idea is that, in a pluralist liberal democracy, it makes sense to give a special seat at the table to those for whom a particular class of subjects or objects are sustained recipients of concern and included in their moral universe; thus, it ought to be possible for a society to move towards greater animal rights without oneself having to identify with animal rights activists in belief or action. The 'greater moral universe' of a given society is the one arrived at by summing the subjects and objects of significant communities of care. This argument is made too quickly, however. Fox points to other directions of research not pursued that arise from the rather condensed chapter, including examining care more thoroughly (I argue that in the United States, animals in research are bounded by the verbs named in their committee, namely care and use, but I only gesture at the richness of caring for and about animals in research that others are exploring so fruitfully), and noticing the role of the law as I did in my work on CITES and the African elephant. She and I agree on the difficulty of resisting human exceptionalism in certain political contexts, and of taking hierarchies seriously in which some humans and some animals are more killable than others, and in which to treat and/or name a human as a non-human animal has long been used as a way of denying humanity.

Overall, like Murphy's and Turkmendag's, Fox's commentary left me educated and excited jointly to raise and pursue new research avenues. I am honoured to have been able to engage with these generous and generative readings; thank you.

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1. As 'an overarching normative term . . . ranging in its application from political contests over funding, rhetoric, and institution-building to matters of personal belief and normative argu- ments made by scholars and activists hailing from a range of disciplines and social locations' (2013: 26).
2. The HO Delivery Plan also highlights conservatism on the part of journal editors and peer review panels to accept publications based on non-animal techniques in lieu of 'traditional' animal models and the difficulties of framing an international consensus to reduce animal research (Home Office, 2014: para 1.3).

Reference

Murphy T (2013) Health and Human Rights. Oxford: Hart.