

Making Human Rights Ordinary in the Bio and Nanotech Era*

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This paper addresses the issue of science related human rights. It begins by showing how science was central yet paradoxically peripheral to the Universal Declaration of Human rights; this is followed by a discussion of the negligible impact of the Nuremberg Code, and the patient rights therein encoded, in the immediate post war. Two conclusions are drawn from these preliminary explorations. First, the interconnection between human rights and science was mediated via the sacralisation of the latter's autonomy from social capture, which in turn limited the types of science related human rights claims that could be made. Second, the explanatory gaze of social scientists should be focused on exploring the concrete configuration of social, political, economic and cultural forces that provide human rights with social efficacy. In other words human rights need to be conceptualised as ordinary objects of sociological analysis.

These two points are further elaborated through a historical case study of the emergence of patient rights in the US, the most important science related human rights to date. This is followed by a discussion on the prospects for science related human rights in the bio and nano era by showing how the knowledge society, risk, scientific citizenship and ELSIfication (i.e. the development of research programs concerned with eliciting ethical, legal and social implications of genomics, nanotechnology, etc.) have weakened, but by no means done away with science's once sacred autonomy. This means that there are currently new opportunities for the emergence of science related human rights claims. It is concluded that science related human rights also raise important issues regarding hybridity and the conceptualisation of human vulnerability.

Keywords: *Science related human rights, patient rights, biotechnology and nanotechnology*

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Introduction

This paper is conceived as an attempt to contribute to the development of a sociological approach to science related human rights. Despite the field of social studies of science's impressively diverse growth and the emergence of a sociological interest in human rights, there has been very little sociological work that has addressed the specificity of science related human rights. In this paper I focus on how human rights have become intertwined with science by drawing attention to how science was both present and absent in the context of the Universal Declaration of Human Rights (UDHR), and by examining the negligible impact of the Nuremberg Code in the post war, despite the normative appeal of its proclamation of individual autonomy and voluntary consent. Drawing on the emerging scholarship on the sociology of human rights, I then go on to argue that one of the ways in which sociology can contribute to understanding human rights is by making human rights ordinary objects of analysis. In order to illustrate this approach I analyse the social trends and processes that led to the institutionalisation of the autonomy of research subjects and informed consent in the US, the most important human right vis-à-vis science to date. I also attempt to show how, in the postwar period, the sacralisation of science's autonomy blocked efforts to broaden citizens' rights vis-à-vis science. In the second part of the paper, in an effort to understand the prospects of making human rights claims in the context of the bio and nano era, I examine how the relationship between the knowledge society, risk, scientific citizenship and ELSification (i.e. the development of research programs concerned with eliciting ethical, legal and social implications of genomics, nanotechnology, etc.) have contributed to the erosion, but by no means the elimination, of science's once sacred autonomy. I conclude, by briefly discussing the need not only to make science related human rights ordinary but also hybrid, and by drawing attention to the relevance but also the difficulty of mobilising the notion of harm and vulnerability in the context of science related human rights.

Linking human rights to science in the UDHR and the Nuremberg Doctors' Trial

The awareness of the Nazi genocidal atrocities was, in the words of Richard Falk, "an essential aspect of the moral consciousness that dominated

the period during and immediately after World War II” (Falk 2009, p. 83). Indeed, he goes on to argue that structurally, ideologically, and geopolitically the post-war period was so little propitious to the moral aspirations and sentiments crystallised in the Universal Declaration of Human Rights (UDHR) that were it not for “the impact of the Holocaust on the political and moral imagination, it is unlikely that even the modest moves to promote international human rights would have been taken in the post-war period of 1945-50” (Falk 2009, p. 88; cf. Somers and Roberts 2008, p. 392). Interwoven in this moral consciousness was the shocking realisation of the enabling role played by science in the creation of the Nazi political imaginary and in the logistics of mass extermination. However, when Alexie P. Pavlov, the Soviet representative in the United Nations Human Rights Commission, asserted that “[a]n atmosphere of terror prevails throughout the world ... It is a terror owing to the application of scientific discoveries for destructive purposes” (Cited in Claude [2002, p. 31]), it is likely that those present were not only thinking about the Holocaust but also about “American responsibility for nuclear destruction in Japan, of the British blanket bombing of civilians in Dresden, and of chemical and biological warfare dreaded by everyone” (Claude 2002, p. 31).

In effect, Richard Pierre Claude, one of the few scholars to explore the links between the UDHR and science, claims that careful examination of the United Nations Human Rights Commission’s deliberations reveals something of an implicit grand theory, in which science and human rights were somewhat naively linked in the pursuit of world peace:

Reduced to its barest elements the underlying logic for a new strategic plan for world peace, said:

- Misguided applications of science in the hands of megalomaniac politicians = war
- Societies empowered by human rights = peaceful social structures;
- Ergo science advancing human rights-friendly society = peace (Claude 2002, p. 34).

Consequently, it was the social misappropriation of science that needed to be checked rather than scientific activity itself. This understanding held across the ideological divide; as is revealed in Pavlov’s swipe at the Americans claiming that they were “creating a danger of extinguishing disinterested scientific research in United States universities in favour of laboratories for military purposes” (cited in Claude [2002, p. 31]). However when Pavlov

when on to assert that “[w]e need to recognize and proclaim the people’s right to enjoy the applications of science mobilized in the service of progress and democracy,” and “the causes of peace and international cooperation” (cited in Claude [2002, p. 33]), Eleanor Roosevelt, the committee’s chair person rebutted: “It seems dangerous to adopt a text which could be interpreted as a pretext for the enslavement of science” (cited in Claude [2002, p. 33]), while the British representative added that “[s]cience should not be placed at the service of an ideology falsely called ‘progress’ as it had been recently when invoked by propagandists of a doctrine bestowing racial superiority upon Germany” (cited in Claude [2002, p. 33]). Similarly the Belgian delegate chimed in that science should not be assigned a political mission, whilst the Australian representative proclaimed: “the sole aim of science could only be the quest for truth” (cited in Claude [2002, p. 33]).

Discursively, then, precisely because of the horror of the Nazi genocidal atrocities and despite the devastation with which science and technology had been mobilised by others in the Second World War as with the blanket bombings of German cities and the detonation of nuclear weapons over Hiroshima and Nagasaki, it was science’s capture by totalitarian ideologies that needed to be avoided. Insofar as science was free to embark on its “quest for truth,” it would be possible, as article 27 of the UDHR stipulates, for all to “share in scientific advancement and its benefits.” Moreover, the rights addressed to everyone, provided

safeguards cognate to the needs of the scientific enterprise because free speech, assembly, and participation as well as rights to intellectual property characterize the conditions scientists need to pursue their professional work effectively because these rights bear on the public’s prospect for enjoying and sharing the application of science (Claude 2002, p. 35).

Nothing more was needed to align science with the progress of human rights. Subsequently this framing was incorporated in the International Covenant on Economic, Social and Cultural Rights (ICESCR) in article 15.3.

In the US post-war period, the coupling of scientists’ right to autonomy with progress and beneficence had been crystallised in 1945 by Vannevar Bush’s report titled *Science — The Endless Frontier*. Bush, an MIT engineer, had chaired the *National Defense Research Committee*, which had been tasked with coordinating the cooperation of civilian scientists with the military during the Second World War. In his report, to President Truman, he argued that the government funding for scientific research that had been ramped up

for the war effort should continue, and should be channelled amongst other things towards the “war on disease,” without completely dismissing its continued relevance to national security. The document, which in effect constituted science’s social contract, is discursively organised around the quite familiar distinction between basic and applied science. The former, he wrote “results from the free play of free intellects, working on subjects of their own choice, in the manner dictated by their curiosity for exploration of the unknown. Freedom of inquiry must be preserved under any plan for Government support of science” (Bush 1945). The role of applied science, predominantly one for industry, was to translate the findings of basic research into technologies that would lead to national progress, prosperity, and well being. In Britain, a similar defence of scientific autonomy had been enunciated, the Haldane Principle, in the 1918 Haldane Report that led to the creation of Britain’s first research council, the Medical Research Council. In a sense, the UDHR merely restated a conception of the autonomy of science, and the concomitant rights of scientists, that were already institutionalised or in the process of being institutionalised. It used the atrocities of Nazi science to signify the dangers associated with meddling with science’s autonomy.

The Nuremberg Doctor’s Trial is a second site where the possibility of invoking human rights in order to curtail science’s autonomy emerges. Conducted under US auspices, 23 defendants were charged with “subjecting unwilling victims to medical procedures that were loosely called ‘scientific experiments,’ thereby having caused their death, disfigurement, or disability” (Jonsen 1998, p. 134). As is well known, the tribunal’s judgement included a ten point ethical code for the regulation of experimentation on human subjects known as the Nuremberg Code (Annas and Grodin 1992, p. 4). Its first point enshrined the principle that “the voluntary consent of the human subject is absolutely essential,” the remaining points dealt with the design, the realisation of, and the balancing of risks in biomedical experimentation. In effect it enunciated a number of constraints on the autonomy of medical and scientific practice. Subsequently this principle would appear both in article 7 of the International Covenant on Civil and Political Rights (ICCPR) and in the 1964 Declaration of Helsinki developed by World Medical Association.

Yet, it would be thirty years before the discursive, political and institutional basis enabling the enforcement of the principles enunciated in the Nuremberg Code would develop into actionable rights in the US and elsewhere. Once again, it seems like the awareness of and the horror produced by the Nazi atrocities made it possible to discursively link the corruption of medical-scientific practice to totalitarianism. This link is

explicitly made by Dr. Leo Alexander, a Tufts Medical School psychiatrist, who was associated with the Nuremberg Doctor's Trial tribunal, in an article published in *New England Journal of Medicine* in 1949. In the article, titled *Medical Science under Dictatorship*, Alexander argued that all forms of dictatorship, regardless of their ideological leaning, were characterized by their espousal of a "Hegelian ... 'rational utility'" in which "doctrine and planning [...] replaced moral, ethical and religious values" (Alexander 1949, p. 39). He then went on to explain how propaganda, the legalisation of euthanasia, and the development of both a science of annihilation and medico-military research had contributed to the denaturing of medical and scientific practice in Nazi Germany. Although in the last section of the article, he raised the issue of the extent to which American physicians had been "infected with Hegelian, cold-blooded, utilitarian philosophy," he nonetheless concluded by listing a number of prophylactic counter-trends associated with democratic society, amongst which he included the development of the pharmaceutical industry.

Consequently, the conclusion to be drawn by those not indicted in the Nuremberg Doctor's trial was that "It was a good code for barbarians but an unnecessary code for ordinary physicians" (Katz cited in Jonsen [1998, p. 137]). This explains the surprisingly low levels of coverage of the trials in the US (Rothman 2003, p. 62). As David Rothman notes, "[t]he events described at Nuremberg were not perceived by researchers or commentators to be directly relevant to the American scene. The violations had been the work of Nazis, not doctors; the guilty parties were Hitler's henchmen, not scientists" (Rothman 2003, p. 63). This despite the fact that many German perpetrators were university trained and appointed researchers with distinguished careers.

In the US, the conditions of possibility for the development of enforceable human rights vis-à-vis science in the form of the rights of patients and research subjects arises, as I show below, from the intersection of a series of events with longer term trends, which led amongst other things to the emergence and institutionalisation of a new form of professional expertise, bioethics. Curiously, however, when one looks at accounts of the development of bioethics and its contribution to the development of patient rights, there is a tendency to invoke the Nuremberg Code as launching off point, this despite the fact it had a negligible impact on regulating the relationship between scientists and their research subjects.

In some sense, this is an artefact of modes of disciplinary knowledge production. As Talcott Parsons succinctly noted philosophy as a knowledge production practice "attempts to achieve rational cognitive understanding of

human experience by methods other than those of empirical science” (Parsons 1949, p. 21). Thus, for a bioethicist the principles enumerated in the Nuremberg Code when not “the most ancient of ethical maxims of medicine, ‘do no harm’” (cf. Jonsen 2007, p. 8) provide adequate starting points for a reflection of the rights of a patient vis-à-vis her physician, without regard for the presence or absence of the specific social relations and processes that underwrite those rights. Threads from the contemporary social fabric are used to weave a social cloth that stretches out and clothes the past. Legal modes of knowledge production, for different reasons, also display an equivalent disregard for the empirical aspects of the social once the “facts” of the case have been determined by reference to the pertinent laws, precedents or authorities (López and Lunau, forthcoming).

There can be little doubt that the semantic affinity between human rights and universality makes possible a variety of politically engaging and normatively compelling discursive effects, organised around discursive nodes such as natural rights, justice, timelessness, inclusiveness, internationalism, cosmopolitanism and globality. Indeed as Bryan Turner has shown, it even makes possible the development of a persuasive normative sociological project grounded in the omnipresence of human vulnerability and institutional fragility (Turner 2006). However, I want to go on to argue that sociology can also contribute to our understanding, and even to the efficacy, of human rights by making them ordinary.

Making human rights ordinary

In advocating for the need to make human rights ordinary, I have in mind the kinds of sociological and social science research that has made it possible to evade the necessity of either naturalising human rights, as some sort of quasi-natural law phenomenon, or reducing them to an imperialist or colonialist ruse (cf. Morgan 2009). In this vein, Anthony Woodiwiss has argued that a more promising point of departure for a sociological understanding of rights is found in the figure of human sacrifice rather than in a mythically retrojected social contract. This is because

just as human sacrifice made sacred both the individual human being and the inequalities that made sacrifice possible, so the sacrifices required by an emergent capitalism made sacred certain aspects of the individual life as god-given, “natural” rights and the inequalities that made the same

capitalism possible. In other words, both “natural” rights and human sacrifice are instances of unequal rather than equal exchange (Woodiwiss 2005, p. 9).

When seen in this way, sociologically at least, human rights, like all socially enforceable rights, offer protection by simultaneously sacralising some dimensions of an individual’s life while sacrificing others. In this sense, making human rights ordinary requires that we treat them as “simply a subset of a larger set of social relations that produce and enforce behavioural expectations, a subset distinguished by their legal form and their focus on the prevention of the abuse of power” (Woodiwiss 2005, p. 4). Said differently, as Somers and Roberts write, “Rights — whether human or citizenship rights or other kinds — are the label we use to characterize certain kinds of social arrangements (Roberts 2008, p. 413). Consequently, the explanatory gaze of social scientists who accept the premise of the ordinariness of human rights should be focused on exploring the configuration of social, political, economic and cultural forces that make human rights appear in their different registers, i.e. “normative moral aspiration,” “codification and doctrine,” and “mechanisms and institutions of enforcement” (Somers and Roberts 2008, p. 388).

With this in mind I want to look at the social processes in the US that opened up a field of social relations in which it became possible to mobilise rights, more specifically the rights of patients and research subjects, in order to minimally curtail the sacralised autonomy of science and medical practice. Following this, I will explore how developments in biotechnology, and more recently in nanotechnology, have led to the expansion of human rights vis-à-vis science, though for the most part in the “normative moral aspiration” register. Thus what follows can be taken as a contribution to the already existing and growing body of sociological research that takes human rights seriously precisely by making them ordinary objects of empirical analysis.

Constraining science in the postwar?

As noted above, the UDHR and the non-pertinence of the Nuremberg Code to anyone but “Nazi barbarians” articulated the potential danger posed by science as resulting from its possible misappropriation by a totalitarian state. In so doing it set up democracy and scientific autonomy as the bulwarks against the possibility of science going bad, whilst providing the

framework through which all might “share in scientific advancement and its benefits.” That said, though the shock waves of the detonation of atomic bombs over Hiroshima and Nagasaki were deflected from the text of the UDHR, its fallout in post-war US society was less easily contained, not least because it was precisely some of the physicists whose work had contributed to making possible the atomic bomb who would subsequently recoil in horror and forcefully make public their anxiety regarding the post-war development of science. In this way, not only did they raise concerns regarding nuclear energy; they also addressed the broader question of the social regulation of science (Stevens 2000, p. 11; cf. Moore 1996). Though the discourse was not framed in terms of human rights, it nonetheless opened up a discursive space in which it was possible to think about constraining science for the greater good, disturbing the link between scientific autonomy and social beneficence.

Tina Stevens argues that this was not the first time that scientists had grappled with the political and social dimensions of their research, but it was

the first time that scientists with the celebrity of the atomic scientists had made their case in so public a fashion. Their influence was extensive, in part, because of the public’s fascination with those who had played such a crucial role in constructing “a doomsday weapon that had killed more than a hundred thousand human beings” (Stevens 2000, pp. 11-12).

By the late 50s and early 60s the political climate produced by loyalty oaths and security investigations would chill much of the activity of the atomic science movement (Moore 1996, p. 1600). However, not before this movement had exerted considerable influence on a group of influential internationally-networked geneticists who would draw parallels between atomic science and genetics, when not direct links (Stevens 2000, p. 12). The latter was expressed as alarm over the impact of nuclear radiation on the quality of a populations’ genetic material. For instance, the 1946 Nobel Laureate in Medicine Hermann Müller publicly expressed his disquiet regarding the prospect that radiation from nuclear weapons, as well as other sources, was causing genetic mutations, the sum of which he believed was causing a “genetic load” that threatened the future existence of humanity (Evans 2002, pp. 49-50). More broadly, though traditional, or to use John Evan’s term “mainline” eugenics, had been terminally discredited as a consequence of its association with Nazi Germany, this did not foreclose its re-emergence in the 50s under the guise of “reform eugenics” in the US.

Whereas the antecedent variant had come to be understood as expressing an irrational and unscientific race and class prejudice, reform eugenicists believed that the “‘valuable’ characteristics to be encouraged in the human species were found across all class and racial groups,” thus they replaced the racial preoccupations of traditional eugenics “with concern about the ‘genetic quality’ — or, for the pessimists, ‘the genetic deterioration’ — of the entire population” (Evans 2002, p. 49).

Other geneticists cognisant of the potential revolutionary implications of genetics were nonetheless alarmed about the emerging reform eugenics discourse, which urged public intervention to curb the debasement of the genetic grade of the population. For instance in 1963, the Italian-born but British based geneticist Guido Pontecorvo, argued, at a Ohio Wesleyan University Conference, that it was imperative to publicly address the possible impacts of genetic research: “[o]nly in this way” he asserted “can we hope to develop ethical standards and democratic means...The alternative is a wise oligarchy knowing and doing what they think good for the rest in the way so vividly pictured by Aldous Huxley 40 years ago in *Brave New World*” (cited in Stevens [2000, p. 19]).

Stevens sums up the impact of the atomic science movement and the politicised geneticists in the following way:

Affected by the responsible science movement and the experience of the atomic physicists, scientists in other fields endeavoured to alert the public to the existence of the biological revolution and to entreat others, from outside science, to assist in the creation of ethical standards to manage this revolution. The calls from such scientists were met by critiques that emerged in the incendiary cultural environment of the sixties (Stevens 2000, p. 19).

Public intellectuals such as Lewis Mumford, Herbert Marcuse, Jacques Ellul and Theodore Rozak would develop more wide-ranging critiques of sciences’ adverse impacts. Indeed by the mid-60s science and scientists “were being blamed for among other things, the war in Vietnam, alienation, decline in the quality of life even as material prosperity increased, and a multitude of environmental problems (Moore 1996, p. 1601). Despite this turbulence, as Kelly Moore has shown, generally scientists were able “to maintain the power to make decisions about science,” and in this way fend off encroachments on their autonomy. Discursively, they did so by claiming that they “acted in the interests of the public”; practically, they embedded these claims in “organizations that now had ongoing linkages to various groups of

nonscientists” thus performatively showcasing “in public settings their commitment to serving the public” (Moore 1996, p. 1620). This, however, was not the case in the context of biomedical research, where the emergence of a new form of expertise, i.e. bioethics, was able to make some inroads into science’s sacred autonomy through the championing of patients’ rights. Although the contribution of bioethics to the institutionalisation of patient rights was significant, its success has to be analysed in a broader social and historical context, to which I now turn.

The emergence of patient rights in the US

The twentieth century saw a number of trends in the evolution of medicine that would, by the 1960s, test when not entirely undermine the relationships of trust that had traditionally governed the interpersonal relationships between family physicians and patients. These included the increased salience and dominance of scientific medicine, the consecration of the hospital as the zenith of medical practice, and the multiplications of medical specialties. These trends contributed to making doctors *Strangers at the Bedside*, the title of David Rothman’s influential history on the curbing of biomedical autonomy. However, it was not just that doctors become strangers; patients were equally transformed through these processes as they metamorphosed into research subjects (Rothman 2003, p. 107).

In addition to this, the development of new medical technologies, particularly those related to emergency medicine — e.g. intensive care units, neo-natal intensive care units, organ transplants — also introduced all manner of questions pertaining to the distinctions between life and death that largely surpassed physicians’ epistemological jurisdiction and the existing ethical codes that governed their profession. In this way, an opening was provided initially to theologians, but more significantly to philosophers and lawyers who were able to successfully expand their epistemological jurisdictions into the medical terrain by establishing themselves as bioethicists. As I will show below, the transformation of applied ethics into a social technology for the production of consensus contributed to securing the stake of the philosophers who ventured into this new terrain.

Law’s success has to be understood in part as a consequence of its salience and the crucial role of the courts in the civil rights and related movements. Indeed as Somers and Roberts note, the initial successes “made the civil rights movement the model template for future law and social

change discourse” (Somers and Roberts 2008, p. 397). In this vein, Rothman writes that

The movements shared an unwillingness to accede to the discretionary authority of whites, men, husbands, parents, clinical investigators, mental hospitals superintendents, elected officials, and of course, doctors, especially when they were males practicing obstetrics, gynaecology, or psychiatry. All the movements subscribed to a fierce antipaternalism, a dogged rejection of the principles of beneficence, and a persistent determination to let constituents speak for themselves and define their own interests. Autonomy and consent became the bywords (Rothman 2003, p. 263).

Moreover, as Rothman goes on to argue both the notions of autonomy and consent owe more to the courts and to legal discourse than to medical ethics or applied philosophy (Rothman 2003, p. 264). Indeed, informed consent in a medical context was given legal standings in US courts in the 1960s (Hoeyer 2007, p. 120). However, notwithstanding the heightened sense of the efficacy of law deriving from its successes in the civil rights context, the contribution of the disciplinary tools of law as a knowledge production practice should not be underestimated (cf. López and Lunau, forthcoming).

Besides the jurisdictional expansion, the heightened sense of contestation of specific social groups, and the longer term trends in the development of medicine noted above, it is important to also register the impact of the pursuit of health as a national objective and the related increase of publicly financed biomedical research. These in turn created a demand for new administrative and regulatory policies but also for public accountability. Amongst other things, the latter was fuelled by a series of well publicised exposés that revealed that individuals who had not or could not have consented had been put at risk as subjects of biomedical research. Famously, in 1966 Henry K. Beecher, a Harvard Medical School anaesthesiologist, published an article in the *New England Journal of Medicine*, ironically the same journal in which Dr. Leo Alexander had published his *Medical Science under Dictatorship*, in which he claimed that

Evidence is at hand that many of the patients in the examples to follow never had the risk satisfactorily explained to them, and it seems obvious that further hundreds have not known that they were the subjects of an experiment although grave consequences have been suffered as a direct result of the experiments described here (Alexander 1966, p. 1354).

In the article he goes on to describe twenty-two instances, “drawn from published articles by leading research scientists” in which the researchers “exposed patients to excessive risks, ignored the need for consent, used poor, mentally incapacitated persons, and withheld therapies of known efficacy” (Jonsen 1998, p. 144). Six years later, the New York Times broke the Tuskegee Story in which

For forty years, the United States Public Health Service has conducted a study in which human beings [all African American] with syphilis, who were induced to serve as guinea pigs, have gone without treatment for the disease...the study was conducted to determine from autopsies what the disease does to the human body” (cited in Jonsen [1998, p. 147]).

It was in this context that in 1979 *the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research* published its report, *The Belmont Report*. The commission had been tasked with identifying “the principles that should underlie the conduct of biomedical and behavioral research involving human subjects, and to develop guidelines which should be followed to ensure that such research is conducted in accordance with those principles” (Bernard Gert, Charles M. Culver, and K. Danner Clouser 1997, p. 73). According to Albert Jonsen, a commission participant, the members of the commission developed a new way of doing ethics:

[b]y going beyond the often chaotic debate that rages around moral issues and beyond the private ruminations of scholars. In this way, a public moral discourse began to evolve, in which a group of citizens seeks the facts of the case, asks for scholarly advice, and enters a debate with a view to resolution (Jonsen 1998, p. 101)

In other words, a new *dispositif* for the production of consensus became available. As Evans notes, it “was portrayed as a ‘philosophy of the people’ — a system that would represent how the public would make decisions if given the opportunity (Evans 2002, p. 73). Out of this process emerged *Principlism*: an applied ethics approach, with significant debts to law, based on the understanding that the relations between human subjects and researchers ought to be governed by the principles of autonomy, beneficence and justice (López 2004a). More concretely, informed consent, and its supporting practices, became the dominant mechanism through which constraint could

be applied on biomedical research through the exercise of individual autonomy. Following this, a complex process unfolds through which *Principlism* and informed consent become the dominant paradigms in funding councils, Institutional Review Boards (IRB), academic journals, medical schools, and bioethics programs (Evans 2002, pp. 89-98), with the bulk of the federal regulation falling in place by 1991 (Goldner 1993, p. 99).

In this way, the autonomy of research subjects, a human right enunciated in the Nuremberg Code, the UDHR and the ICCPR in a “moral normative register,” has become institutionalised in the US through the construct of informed consent. Although it would be possible to look back and see the development as a gradual extension of an idea seeded in the past — a frequent narrative trope in human rights discourse (Woodiwiss 2009, p. 107) — sociologically it is better understood as the outcome of the concatenation of social processes and events that produced the transformations of social relations described above. I would like to develop two points from this discussion.

The first is that this specific human right, autonomy grounded in informed consent, arises in the context of what Woodiwiss has called the “major tradition” (Woodiwiss 2009, p. 108), that is to say the narrower set of civil and political rights associated with the liberal emphasis on individual autonomy and self-determination, as distinct from the “minor tradition” based on the principle of reciprocity. Despite this, scholars have identified important shortcomings concerning its efficacy (cf. Corrigan 2003; Corrigan et al. 2009). This is hardly surprising, seen from the perspective of the Woodiwissian figure of rights as sacrifice, the ability to circumscribe the power of biomedicine by sacralising informed consent serves to reproduce and consecrate the inequality between research subject and researcher and the particular social, economic and political relations through which health as a social phenomenon and medical practice position individuals. Moreover, the question of adequacy becomes even more complicated when the “ideals” of informed consent and autonomy are taken abroad to contexts governed by different configurations of social relations. In particular it has been noted that in the absence of cultural references and social arrangements that create a field for the exercise of autonomy, informed consent is meaningless at best (Claude 2002, p. 89). More worrisome is the fact that as the recruitment of research subjects has become more costly and constrained in Western countries as a result of strict regulations and safety and compensation measures, courtesy of patient rights, a new global political economy of clinical drug trials is taking form in non-Western countries where inadequate

regulations, illiteracy, poverty and vulnerability keep costs down (Nundy, Chir, and Gulhati 2005, p. 1633). Moreover, as Sunder Rajan (2008) has shown, even in the context of well regulated sites such as clinical research organizations (CROs) in India, ethical safeguards contribute to the depoliticisation of the research subjects whose physiologies perform the high risk labour required to get drugs to market in biocapitalism. Thus, although I will not develop this idea further here, it is clear that informed consent as an instantiation of the human right of autonomy is vulnerable to the criticisms that are raised more broadly regarding the insufficiency of human rights in the major liberal tradition, i.e. the narrower range of civil and political rights, both in those social contexts in which there is a socially-structural affinity as is the case in Western countries, but especially outside of them.

The second point is that currently, and no doubt related to processes in other spheres of human rights (cf. Blau and Moncada 2005; Woodiwiss 2005, chap. 11-12) there is evidence of a potential for expanding the scope of human rights vis-à-vis science. For instance a number of European countries have explicitly invoked human rights in the context of healthcare, biotechnology, and the environment by emphasising notions such as “solidarity, human dignity and collective good” (Knowles 2001, p. 256). In 1997, the General Conference of UNESCO adopted the *Universal Declaration on the Human Genome and Human Rights* (UDHGHR), the first universal human rights tool dealing with biology. More importantly, however, human dignity and the human rights to health (Benatar 2000; Freeman 2009), food (Gonzalez-Pelaez 2005; Shiva 2000), and culture have been summoned in a variety of contexts to contest intellectual property rights (Cullet 2007; Sell 2001), repel the encroachment of agricultural and medical biotechnology (Krimsky and Shorett 2005), and rebuff biopiracy (Greene 2002; Lock 2001; Katy Moran, Steven R. King, and Thomas J. Carlson 2001). Thus the human rights’ “minor tradition” vis-à-vis science, i.e. the notion that human rights are sometimes better served by constraining science’s autonomy, finally seems to be getting traction. This tradition, as I have shown above, surfaced in the deliberations of the United Nations Human Rights Commission but was excluded from the UDHR; it reappeared in the US post-war responsible science movement and the radical critiques of science but was shut out by the sacralisation of science’s autonomy. However, it is far too tempting to read this, unsociologically, as an instance of some developmental logic intrinsic to human rights. In order to foreclose this possibility and to see these potential rights as ordinary, I want to outline some of the trends and processes that have made it possible for human rights as well as other social arrangements

to question science's sacred autonomy.

Science's autonomy in the knowledge Society

One of the reasons why it is now possible to question science's once sacred autonomy is that to a very significant extent its social-structural conditions of possibility have been transformed. The distinction between a self-governing autonomous "pure" science that enabled "the free play of free intellects" and technology, which was central to the Vannevar Bush vision, is no longer operative. Indeed science studies scholars have argued that insofar as contemporary scientific activity is organised around the pursuit of more immediate social goals, we are now within the territory of technoscience. For instance, in their seminal text, *The New Production of Knowledge*, Gibbons et al. (1994) made a distinction between Mode 1 and Mode 2 science. Whereas in the former the development of science is understood to be powered by the interests and curiosity of the scientific community narrowly conceived, in the latter it is oriented towards problem-solving in the context of application. Consequently Mode 2 science is made to be more susceptible to the needs of the different "stakeholders," and is required to account for itself more pragmatically in terms of social benefits, innovation, and contributions to economic growth. In this sense, according to Nowotny et al., "not only does science speak to society (it always has), but the conditions are established in which society can 'speak back' to science" (Nowotny et al. 2002, p. 245). Seen thus, the mobilisation of support and resources from diverse and heterogeneous constituencies, such as venture capital, NGOs, regulators, the media, citizen groups, patient groups, consumer association and regulators becomes an integral dimension of technoscientific practice (Nowotny et al. 2002, p. 246).

These changes of course cannot be understood as deriving from a developmental logic immanent to science itself, they are better grasped in the context of the social, political, economic, and ideological transformations associated with what Daniel Bell had prefigured as a Post-Industrial and today is more commonly referred to as the knowledge society or the knowledge economy (Nowotny et al. 2002). As a political imaginary, the discourse of the knowledge society synergistically welds together new modes of knowledge production, innovation and entrepreneurship, freedom from restraint, global competitiveness, economic growth and national wellbeing. As a social formation, it has required amongst other things

the widespread currency of neoliberal rationalities as modes of economic and political governance, the increasing corporatization of universities and of funding councils, changes in tax regimes for R&D, the institutionalization of new private-public funding hybrids, modifications to patent law, attempts to strengthen intellectual property protection at global level, developments in technology as well as the increased saliency of globalist discourse (López and Robertson 2007, p. 210).

Human Rights in the bio and nanotech era

Although information and communications technologies were and continue to be a major axis of the knowledge economy, biotechnology has been no less significant; in fact, in the early 80s, genetic engineering was depicted as “the core technology of a new industry, biotechnology, which was expected to have a revolutionary impact on both society and economy” (Gottweis 1998, p. 153; cf. Jasanoff 2005). The ensuing “Biomania” condensed a number of elements that confirmed biotechnology’s privileged place within the emerging knowledge economy. These included the market rallies around the first public listing of biotech companies, the hype and hope with which its technologies were projected into the future, and the perception in Europe that it was necessary to follow the US lead down the biotech path in order to remain competitive (Gottweis 1998, p. 156).

Melinda Cooper has persuasively argued that biotechnology’s distinctive position within the knowledge economy has to be analysed in the context of the decline of US competitiveness in the 60s and 70s, the related perception that the economic model, which had served the US so well in the postwar, was in crisis as well as the growing impact of the environmental movement. This perception of crisis was condensed in the Club of Rome’s world futures report of 1972, which ominously not only put in question the postwar model of economic growth but also the biosphere’s capacity to continue supporting life (Cooper 2008, p. 16). This was because the economic growth needed to service the exponential increase in population would collide with insurmountable limits: “These limits were of two kinds, consisting not only in the depletion of non-renewable resources but also in the steady environmental buildup of toxic, non-biodegradable waste” (Cooper 2008, p. 16). The organic intellectuals of the new right and of the post-industrial society heavily criticised the report for being trapped in the paradigm of quantitative intensification and thus failing to grasp the potential associated

with a qualitative change in the organisation of social and economic life, in which an innovation-based economy would harness the power of human creativity not only to overcome economic decline, but also to surmount the so-called environmental limits (Cooper 2008, p. 18).

Petrochemical industries, which produced all manner of chemical products, plastics, fabrics and agricultural goods, such as fertilizers and herbicides, were particularly hard hit by the economic downturn and the rise of environmentalism. Major pharmaceutical companies were also vulnerable because their product development pipes were running dry, their compounds were losing market share to generics, and they were also receiving flak from patient rights advocacy groups. It is in this context that biotechnology's potential for the knowledge economy was cultured by the major petrochemical and pharmaceutical companies, which seized on the development in recombinant DNA technologies to re-brand themselves as "purveyors of the new, clean life science technologies" (Cooper 2008, pp. 21-22). Thus the 80s and 90s saw the consolidation of the Life Sciences Company approach, spearheaded by such industrial giants as Monsanto, Novartis, Aventis, Zeneca, Bayer and BASF (cf. Bowring 2003, chap. 3). Moreover because biotechnology was discursively framed as mobilising the natural potential of "life" it was possible to position it against the toxic and waste-producing activities of the Fordist industrial economy:

the unique character of the technology is that it is fully biological, composed of the workings of genes, proteins, cells and tissues. On the one hand, biotechnology appears not to be a technology at all, but only "life itself" rearranged or recontextualised, but nevertheless performing the same functions it always has (Thacker 2005, p. XIX).

Consequently, discursively biotechnology's potential within the imaginary of the knowledge economy resided in being able to overcome "the geochemical laws ruling over Fordist industrial production" with "the much more benign, regenerative possibilities of biomolecular production" (Cooper 2008, p. 23). In this way, the future could become associated not with limits to growth, but precisely with the erasure of the very notion of limits, which perhaps goes a long way towards explaining the tendency, noted by science studies scholars and others, for extreme hype in the biotechnological sector where "various areas of technological innovation become saturated with stratospherically high expectations of immanent and revolutionary change" (Brown 2003, p. 4).

According to Cooper, the notion of “promise” is a vital dimension of the knowledge economy, hence also of biotechnology, and of the neoliberal rationality that underpins it: “promise is what enables production to remain in a permanent state of self-transformation, arming it with a capacity to respond to the most unpredictable of circumstances, to anticipate and escape the possible “limit” to its growth long before it has even actualized” (2008, p. 24). Because of this, speculation in the form of potential economic windfalls or through the extrapolation of the therapeutic or beneficent future effects of specific biotechnologies provides not only a mechanism for locking in the diverse constituencies that need to be mobilised within the context of Mode 2 science, but also reiterates biotechnology’s conditions of emergence within the imaginary of the knowledge economy. It also in part explains the centrality of patents, not only in terms of temporal extension of patents and securing their operability globally, which have been so important for the biotechnology industry (cf. Sell 2003), but also the intensity and expansiveness with which patents have been sought. As a result of a radical future orientation, “in the absence of any tangible assets or actual profits, what the biotech start-up can offer is a proprietary claim over the future life forms it might give rise to, along with the profits that accrue from them” (Cooper 2008, p. 28).

Elsewhere, I explore at length how nanotechnology is currently outdoing biotechnology at the level of the exuberance of its promissory notes (López 2004b; López 2008). In part this is a consequence of how nanotechnology is discursively positioned vis-à-vis the question of the ecological, natural, and social limits of economic growth. At present the field of nanotechnology remains rather fluid and heterogeneous (cf. López 2004b; López 2008). Typically, though, nanotechnology is defined in terms of the ability to work at the nanoscale — a nanometer equals 1 billionth of a meter — but more importantly to work with physical, chemical, or biological properties that exist at this scale. Defined thus, the potential associated with nanotechnology has been extrapolated in a number of ways. For instance, it is possible to envision nanoarchitectures that will enable the interface of organisms and machines with high degrees of precision leading to a new generation of pharmaceutical compounds, vectors for their delivery, tissue regeneration, as well as a new class of medical diagnostic, visualization and monitoring devices. Beyond biomedicine, new nano-engineered computing and communications frameworks have the potential not only to provide speedier and exponentially more powerful computing capabilities, but also the fabrication of physical and biological environments endowed with sensing

devices rendering them both intelligent and adaptable. Furthermore, since it is at the nanoscale where the major macroscopic properties (strength, malleability, conductivity, etc.) are defined, all manner of stronger, more conductive and flexible materials have been anticipated. Finally, the expectation is that all of these dimensions will synergistically interact with each other producing multiplier effects where for example new materials will increase computing power that will enable the fabrication of more efficient biosensors, which will loop back into the production of yet more enhanced materials, etc.

Despite the lack of uniformity, or perhaps precisely because of it, the emergent field of nanotechnology has been framed around a discursively powerful metaphor: the nanotechnology scientist as the master builder. Frequently, in nanotechnology texts, nature is anthropomorphised into an engineer that assembles matter one atom at a time. In this way, as with biotechnology, nanotechnology is discursively positioned as reproducing natural processes, thus in important ways not being a technology at all and just being nature's way of doing things, 100% naturally as it were. Moreover, as I show elsewhere (López 2004b; López 2008) insofar as it is claimed that nanotechnology scientists work on and with the fundamental "building blocks" of reality, nanotechnology is framed as "the builder's final frontier" (Smalley cited in López [2004a, p. 133]), and it becomes possible to conceive of re-building the world (inorganic, organic and social!) one atom at a time. In this manner, nanotechnology is able to overcome the future claims of biotechnology that for all of their exuberance remained tied to the domain of the organic world, of life itself. Unsurprisingly, the claims made on behalf of biotechnology's ability to overcome physical, economic, organic, social and environmental limits have been reissued by the promoters of nanotechnology, but in a new re-engineered and upgraded form, version 2.0 so to speak (López 2008).

In spite of the attempt to first twin biotechnology and now nanotechnology with nature itself, this frame has been highly contested. One need not accept the epochal characterisation of the emergence of risk society or the second modernity thesis (Beck 1992) in order to recognise the significance of risk for contemporary social formations. Chernobyl, Bhopal, DDT, Thalidomide, BSE, Climate Change amongst others have served, as Sheila Jasanoff has argued, "collective notice that human pretensions of control over technological systems need serious re-examination" (Jasanoff 2003, p. 223). One of the effects of this call to order has been the enlargement of the constituencies empowered to participate in the determination of risks,

specially as Jerry Ravetz has argued in the context of decisions about safety where “facts are uncertain, values in dispute, stakes high and decisions urgent” (Ravetz 2005, p. 45). Moreover, the hyperbolic claims made on behalf of biotechnology — i.e. a new industrial era, miraculous cures, harnessing life itself, sourcing the code of life, deciphering and rewriting the book of life — have provoked negative reactions of great intensity apropos the prospects of new eugenic projects and new modalities of genetic discrimination, the dangers of playing God, the patenting and commercialisation of organisms and life processes, Frankenfoods, biopiracy, and irreversible environmental damage. In the case of nanotechnology, its utopian projections have unsurprisingly elicited equally dystopian responses, e.g. the grey-goo hypothesis, but also less catastrophic yet substantial concerns with respect to nanoparticle toxicity, control over the information gathered by nano-devices and their decision-making capacity, human enhancement and military applications. Consequently the contemporary dynamics of risk as they relate to scientific and technological development have made it possible to contest the autonomy of scientific progress by mobilising not only the potential for individual but also for collective harm.

In response to the politicisation of risk but also as a result of the need to mobilise and enable citizens to fulfill their roles in the knowledge society, governments at all levels (municipal, regional, national and transnational) have been concerned with developing new modes of governance, or of rule, that are productive of scientific citizenship. Neoliberal rhetoric to the contrary, the rationalities of neoliberal governance are not just restricted to rolling-back the state but have also involved rolling it out in particular spheres. These have taken a number of different forms such as stimulating interest in science and technology, promoting scientific literacy and developing new strategies for improving the public understanding of science, the identification of relevant stakeholders, public consultation and deliberation, citizen’s juries, consensus conference, etc. (cf. Irwin and Michael 2003). Although these represent attempts to mobilise support for the relevant technologies and rationalities of scientific citizenship, they have also provided points where and around which opposition and resistance have been and can be expressed.

In addition to these initiatives, a number of ELSI (Ethical Legal and Social Implications of genomics, nanotechnology, etc.) programmes have been launched. The first ELSI programme was created as a component of the US Human Genome Project, the US contribution to the international effort to sequence the human genome. An artefact of the knowledge society, it was

tasked with anticipating and resolving problems and contributing to the development of policy that would maximise the benefits for individuals and society, as well as stimulating public discussion. Since then, “ELSIfication” has become de rigour with all new major scientific initiatives. ELSI programs have been criticised widely because they have been perceived as being too closely aligned with the objectives of the scientific endeavours that they were meant to scrutinise (cf. López and Robertson 2007), and as a consequence have been relegated to the role of facilitating the development and adoption of new technologies (Williams 2006, p. 334).

As we have shown in our analysis of the development of ELSI in Canada (López and Robertson 2007), bioethicists and legal scholars, the same groups that contributed to the development of patients’ rights, were well positioned to expand their epistemological jurisdiction over a so-called interdisciplinary field that was bizarrely defined by the absence of an empirical or conceptual object of analysis. They were able to scale up the tools for the governance of the relationships between human subjects and research to the societal governance of biotechnology. An interesting illustration can be found in the now disbanded Canadian Biotechnology Advisory Committee’s (CBAC) effort to include Canadians in the governance of biotechnology. The committee reasoned that given the impossibility of physically including all Canadians they could do so through the proxy of Canadian values, i.e. if the values of Canadians were the ones used to govern biotechnology then in effect Canadians would be participating, albeit indirectly. Stunningly, the values that CBAC generated as Canadian values were in fact those values used to regulate research on human subjects, with a few minor modifications (López and Robertson 2007).

Because, by the 1990s, when the US and the Canadian ELSI projects were launched, bioethics was well institutionalised and the link to the Nuremberg Code, the UDHR and ICCPR had been retroactively established, human rights became an integral component of bioethics’ ELSI discourse (cf. Knoppers 1991). Moreover, ELSI represented the institutionalization of one of the elements that had contributed to the emergence of patient rights. As I noted above, the process that produced the Belmont Report was described as a new way of doing ethics: “a philosophy of the people’ — a system that would represent how the public would make decisions if given the opportunity” (Evans 2002, p. 73). Thus insofar, as ELSI programs recognise that science impacts citizens and society and its effects should be scrutinized, it provides citizens with the right to constrain science’s autonomy, but only by proxy, through the intermediary of a social technology for the production of

consensus. Equally, the global scope of biotechnology (Thacker 2005) offered a good fit with the universalistic aspirations of human rights tools. In addition to this, whereas in the UDHR the reference to the membership in the “human family” seemed vague if not metaphysical, in the UDHGHR the claim that “the human genome underlines the fundamental unity of all members of the human family” provides a tangible material basis for the familial reference. This is because the human genome is simultaneously individual and collective: the complex interaction of each person’s genome with their environment is what makes them unique but also links them to humanity’s past, present and future. Indeed the Canadian but internationally networked bioethicist Bartha Knoppers has argued that the informatic and genomic revolutions, the internationalisation of bioethics, and the adoption of the declaration, have given rise to a third generation of human rights (Knoppers 2000, p. 259). What are we to make of this claim? In my concluding remarks, I summarise the implications of the processes that have led to science’s loss of autonomy and what they entail for a sociological understanding of human rights vis-à-vis science.

Conclusion

I have argued that the feasibility of expanding the claims of human rights with respect to science beyond the parameters of informed consent, which itself only emerged in the US and elsewhere in the late 60s, had been blocked by the simultaneous linking of humanity’s ability to benefit from the progress of science to the latter’s autonomy, Vannevar Bush’s *Endless Frontier*. However, insofar as science’s autonomy has been reconfigured as a result of its mobilisation for the knowledge economy, initially through biotechnology and now also with nanotechnology, science has had to respond to a broader constituency and their interests, i.e. Mode 2 science. A number of critics have noted that the claim-making has been asymmetrical (cf. Delanty 2001, pp. 112-13; Pestre 2003). Indeed, one can agree that science’s autonomy has never been so vulnerable, but that this vulnerability has been to capitalism’s advantage. That said, it has been biocapitalist practices such as intensive and extensive patenting strategies, the enforcement of intellectual property rights and bioprospection that have provoked human rights based responses and successes, i.e. the Third World Network and RAFI’s derailment of the Human Genome Diversity Project (M’charek 2005, p. 12), the development of profit sharing regimes (Parry 2004) and the numerous challenges to life form

patents and pharmaceuticals related to the human rights to food and health (Sell 2001). Moreover, efforts to erase the “tech” from biotechnology and nanotechnology in order to “greenwash” them as well as attempts to frame these technologies as being capable of overcoming ecological, natural and social limits, have had the surely unwilled effect of politicising risk leading to calls for and the development of more collective modes of risk evaluation and decision making. This has led to the reconfiguration of social relations and the creation of social practices through which the autonomy of science might be made subject to collectively designated goals and risk tolerance.

Likewise, the need to develop modes of governance such as scientific citizenship in the knowledge society has produced some unintended consequences. By linking citizenship to science and technology, these processes, at least in a “normative moral aspiration” register, have produced a situation where it is increasingly difficult to address “citizenship or deliberation or accountability without delving into their interaction with the dynamics of knowledge creation and use” (Jasanoff 2005, p. 6). This in turn contains the potential for re-describing and reconfiguring the narrower civil and political rights to enable the democratisation and collective determination of the processes through which science and technology are steered. Equally, though ELSIism has on the whole been devoted to adapting the rights of informed consent and patient autonomy to the bio and nanotech era, the institutionalisation and the contemporary obligatory nature of ELSI type programs continue to provide sites in which and through which it is possible to expand rights vis-à-vis science.

I concluded the previous section by asking what one was to make of Bartha Knoppers’ proclamation of the arrival of the third generation of human rights represented by the adoption of the UDHGHR, which she describes as the culmination of an evolutionary process whose previous stages included political freedoms and civil rights, followed by socio-economic rights. A careful reading of the declaration reveals, however, that despite the provision in Article 4 that “the human genome in its natural state shall not give rise to financial gains,” hardly an obstacle for biotech corporate lawyers, the focus is overwhelmingly on individual autonomy and the fostering of research development, with some ELSI type constraints. Not much of a departure from the UDHR or the ICCPR. In fact, the UDHGHR represents an attempt to internationalise science related human rights using the tools of informed consent and constraint via the ELSI proxy, the forms that science related human right have taken in the US and Canada. Moreover, less an attempt be made to mobilise human dignity to enunciate some type of

broader constraint on the freedom of scientific research, which could bypass ELSI's control, as has been the case with stem cells research, some ELSIists have endeavoured to limit the development of this "dignitarian" discourse by tethering science related human rights tightly to informed consent, individual autonomy, and rational consensual policy making (cf. Caulfield and Brownsword 2006), a sure way of reducing politics to ethics (cf. López and Robertson 2007).

Seen thus, there is not much to be hopeful about. However if one conceptualises science related human rights as ordinary object of analysis, as I have attempted to do in this paper, it is possible to be a slightly more optimistic. As a consequence of the way in which science's sacred autonomy has been eroded by the ordinary social-structural processes described above, the "moral normative aspiration" of expanding human rights vis-à-vis science now has the potential of being coupled with a number of emerging mechanisms, institutions and social surfaces, though this does not mean that they will. Moreover, insofar as some of these are a response to the neo-liberalisation of science, they draw or could draw on other efforts that have mobilised human rights in order to roll back the contemporary reach of global capitalism (Blau and Moncada 2005).

In this paper my emphasis, driven by my empirical objects of analysis, has been on some of the broader trends in the US, Canada, and Europe and some aspects of the globalisation of bioethics and ELSIism. A sociological understanding of the ordinariness of science related human rights would need to explore some of these mechanisms, institutions, and social spaces in more detail in order to explain for instance why genetically modified organisms have been framed as a human rights issue in Europe but not in the US (cf. Jasanoff 2005). Naturally, a more cosmopolitan research agenda would need to be undertaken in order to explore the prospects of constraining science's autonomy in contexts governed by different cultural and social structural configurations. It would also need to address the impact of the other significant technologies associated with the knowledge society, information and communications technologies, which I have not dealt with here but which are elaborately entwined with both bio and nanotechnology.

In addition to making human rights as they relate to science and technology sociologically ordinary, and unfortunately this is a point that I can only make in passing here, human rights would need to be conceptualised as hybrid as well. In invoking the notion of hybridity in this context, I am referring to what must certainly be the Archimedean point around which contemporary science studies has developed: the problematisation of the

nature/social distinction by conceptualising social life as being constituted not only through relations among social things but also through relations with non-human “natural” things (cf. Latour 1993). There are important metatheoretical consequences associated with summoning the idea of hybridity as conceptualised in science studies. However, my purpose here is simply to draw attention to the fact that the different forms in which scientific and technological knowledge and practices materialise — e.g. bioinformatic databases, patents, “wet” databases,” synthetic biology — both determine and are determined by social relations. Consequently if we are serious about trying to understand the development of human rights as they impact and are impacted by fields such as biotechnology and nanotechnology, we have to conceptualise human rights as arising in a hybrid space, a field of relations that are simultaneously “social” and “natural.” This is not a rejection of scientific realism, but rather the recognition that scientific knowledge and practice represent the point where nature and the social meet and not a process where the latter is purified from the former.

Let me briefly illustrate the importance of grasping the different ways in which scientific knowledge materialises the biological or the natural, and how these different materialities affect both the formation of rights as do conceptions of rights affect the products of science and technology. The emergence of protocols for profit sharing and biodiversity, especially in the context of bioprospection have been put forward as an illustration of a more enlightened and equitable human rights approach to the question of who should benefit from developments in biotechnology. However, contemporary biotechnology as Eugene Thacker (2005) has shown, has to be understood as a series of material, social, and economic practices where biological processes are encoded into information, recoded through sophisticated bioinformatically enabled tools where the information is mined and or recombined, and then decoded into material artefacts such as a drugs, organisms or diagnostic devices. One of the consequences of bioinformatics becoming dominant, though not necessarily determinate, in biotechnology is, as Browlyn Parry has shown in her study of the commodification of bioinformation, that biological resources

can now be conveyed in a partially decorporealized or even wholly informational form, as a sample of genetic material, a biochemical extract, or even a coded sequence of DNA. When in these forms, they are more transmissible, modifiable and replicable. These factors have acted to create a new economy in bio-information, but they will also serve to make this new

economy particularly difficult to regulate (Parry 2004, p. 100).

In this context the profit sharing protocols become more difficult to enforce while the intellectual proprietary rights that ensue from the dry lab are strengthened. Similarly, as the ETC group has noted in its report on nanotechnology patents, while the “patenting of life” in the form of novel organisms, re-engineered tissues or other biological processes has caused much public concern, little notice has been taken of the patenting practices of the nanotechnology industry. However, the patenting of enabling tools, processes and materials at the nanoscale in fact could lead to proprietary claims that are potentially more wide ranging than those found in the field of biotechnology, thus authorising new forms of the economic exploitation of nature and requiring new strategies in order to enable communities to defend their rights over traditional herbal and medicinal remedies (ETC Group 2005).

Finally, I would like to conclude by addressing how sociology might contribute to a normative grounding of human rights vis-à-vis science. In order to do so, I would like to invoke two notions that are central to the development of human rights more generally, i.e. harm and vulnerability, in order to suggest that they need to be rethought in the context of science related human rights. Much of the normative power associated with human rights derives, as Bryan Turner has argued, from our common vulnerability to pain and suffering, which arises from our physical embodiment and the fragility of social institutions. It is the certainty that torture produces pain, that inequality produces ill-health, that a lack of access to food produces starvation, and that the absence of recognition and political and social rights produce suffering that makes human rights so compelling and the need to institutionalize them so urgent. However, if we have learnt anything from the immense body of research produced by the social studies of science it is that scientific and technological development is non-linear and frequently radically unpredictable. Our fragility vis-à-vis scientific and technological development does not arise from the certainty of harm but rather from the lack of certainty.

I think that it is important not to confuse an argument for the expansion of human rights vis-à-vis science with an argument against science. Only a Luddite would deny the prospect that biotechnology and nanotechnology will produce innovations that will be beneficent and socially useful. However, only hubris could make us think that these technologies can be developed without causing harm and perhaps even producing irreversible catastrophic

events. It is for this reason that I think we should think about science related human rights not primarily as a mechanism for introducing prohibitions on scientific practice, though in some cases this may be necessary, but as a way of developing social practices and rights that recognise our common fragility vis-à-vis the unknown and unknowable. What I have in mind is conveyed by Sheila Jasanoff's notion of technologies of humility:

that is to say methods and habits of thoughts, that try to come to grips with the ragged fringes of human understanding – the unknown, the uncertain, the ambiguous and the uncontrollable. Acknowledging the limits of prediction and control, technologies of humility confront 'head-on' the normative implications of our lack of perfect foresight. (Jasanoff 2003, p. 22)

Such an understanding provides a powerful normative grounding for science related human rights that arise from our shared fragility vis-à-vis the unknown that scientific development represents.

References

- Annas, George J., and Michael A. Grodin, eds. 1992. *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation*. Oxford: Oxford University Press.
- Beecher, Henry K. 1966. "Ethics and Clinical Research." *The New England Journal of Medicine* 274 (24): 1354-60.
- Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage.
- Benatar, Solomon R. 2000. "The Biotechnology Era: A Story of Two Lives and Two Worlds." Pp. 245-57 in *Peace, Justice and Freedom: Challenges for a New Millennium*, edited by Gurcharan S. Bhatia, J. S. O'Neill, Gerald L. Gall, and Patrick D. Bendin. Edmonton: University of Alberta Press.
- Beyleveld, Deryck, and Roger Brownsword. 2001. *Human Dignity in Bioethics and Biolaw*. Oxford: Oxford University Press.
- Blau, Judith, and Alberto Moncada. 2005. *Human Rights: Beyond the Liberal Vision*. Boulder: Rowman and Littlefield Publishers.
- Bowring, Finn. 2003. *Science, Seeds and Cyborgs*. London: Verso.
- Brown, Nik. 2003. "Hope against Hype — Accountability in Biopasts, Presents and Futures." *Science Studies* 2: 3-21.
- Bush, Vannevar. 1945. *Science the Endless Frontier: A Report to the President by Vannevar Bush, Director of the Office of Scientific Research and Development*. Washington: United States Government Printing Office.

- Caulfield, Timothy, and Roger Brownsword. 2006. "Human Dignity: A Guide to Policy Making in the Biotechnology Era?" *Nature Reviews: Genetics* 7 (11): 72-76.
- Cooper, Melinda. 2008. *Life as Surplus: Biotechnology and Capitalism in the Neoliberal Era*. Seattle and London: University of Washington Press.
- Corrigan, Oonagh. 2003. "Empty Ethics: The Problem with Informed Consent." *Sociology of Health and Illness* 25 (3): 768-92.
- Corrigan, Oonagh, Kathleen Liddell, John McMillan, Martin Richards, and Charles Weijer, eds. 2009. *The Limits of Consent: A Socio-Ethical Approach to Human Subject Research in Medicine*. Oxford: Oxford University Press.
- Claude, Richard Pierre. 2002. *Science in the Service of Human Rights*. Philadelphia: University of Pennsylvania Press.
- Cullet, Philippe. 2007. "Human Rights and Intellectual Property Protection in the TRIPS Era." *Human Rights Quarterly* 29: 403-30.
- Delanty, Gerald. 2001. *Challenging Knowledge: The University in the Knowledge Society*. Buckingham: Open University Press.
- ETC Group. 2005. *Nanotech's "Second Nature" Patents: Implications for the Global South*. http://etcgroup.org/en/node/54?pub_id=54
- Evans, John H. 2002. *Playing God? Human Genetic Engineering and the Rationalization of the Public Bioethical Debate*. Chicago: Chicago University Press.
- Falk, Richard. 2009. *Achieving Human Rights*. New York: Routledge.
- Freeman, Michael. 2009. "The Right to Health." Pp. 44-67 in *Interpreting Human Rights: Social Science Perspectives*, edited by Rhiannon Morgan and Bryan S. Turner. London: Routledge.
- Gert, Bernard, Charles M. Culver, and K. Danner Clouser. 1997. *Bioethics: A Return to Fundamentals*. New York and Oxford: Oxford University Press.
- Goldner, Jesse A. 1993. "An Overview of Legal Controls on Human Experimentation and the Regulatory Implications of Taking Professor Katz Seriously." *Saint Louis University Law Journal* 38: 63-134.
- Gonzalez-Pelaez, Ana. 2005. *Human Rights and World Trade: Hunger in International Society*. London: Routledge.
- Gottweis, Herbert. 1989. *Governing Molecules: The Discursive Politics of Genetic Engineering in Europe and United States*. Cambridge MA: MIT press.
- Greene, Shane. 2002. "Intellectual Property, Resources or Territory? Reframing the Debate over Indigenous Rights, Traditional Knowledge and Pharmaceutical Bioprospection." Pp. 229-49 in *Truth Claims: Representation and Human Rights*, edited by Mark Philip Bradley and Patrice Petro. New Brunswick, NJ: Rutgers University Press.
- Hoeyer, Klaus. 2007. "Ethics Regulation in the Field of Medicine: A Historical Sketch." *Harvard Health Policy Review* 8 (1): 5-15.
- Irwin, Alan, and Mike Michael. 2003. *Science, Social Theory and Public Knowledge*.

- Maidenhead: Open University Press.
- Jasanoff, Sheila. 2003. "Technologies of Humility: Citizen Participation in Governing Science." *Minerva* 41 (3): 223-44.
- _____. 2005. *Designs on Nature*. Princeton: Princeton University Press.
- Jonsen, Albert R. 1998. *The Birth of Bioethics*. Oxford: Oxford University Press.
- _____. 2007. "A History of Bioethics as Discipline and Discourse." Pp. 3-16 in *Bioethics: An Introduction to the History, Methods and Practice*, edited by Nancy Ann Silbergeld Jecker, Albert R. Jonsen, and Robert A. Pearlman. Boston, MA: Jones and Bartlett Publishers.
- Knoppers, Bartha Maria. 1991. *Human Dignity and Genetic Heritage*. Ottawa: Law Reform Commission of Canada.
- _____. 2000. "Human Rights and Genomics." Pp. 259-65 in *Peace, Justice and Freedom: Challenges for a New Millennium*, edited by Gurcharan S. Bhatia, J. S. O'Neill, Gerald L. Gall, and Patrick D. Bendin. Edmonton: University of Alberta Press.
- Knowles, Lori P. 2001. "The Lingua Franca of Human Rights and the Rise of a Global Bioethics." *Cambridge Quarterly of Healthcare Ethics* 10: 253-63.
- Krimsky, Sheldon, and Peter Shorett, eds. 2005. *Rights and Liberties in the Biotech Age*. New York: Rowman and Littlefield Publishers.
- Latour, Bruno. 1993. *We Have Never Been Modern*. Cambridge, MA: Harvard University Press.
- Lock, Margaret. 2001. "The Alienation of Body Tissue and the Biopolitics of Immortalized Cell Lines." Pp. 63-91 in *Commodifying Bodies*, edited by Nancy Scheper-Hughes and Loïc Wacquant. London: Sage.
- López, José Julián. 2004a. "How Sociology Can Save Bioethics ... Maybe." *Sociology of Health and Illness* 26 (7): 875-96.
- _____. 2004b. "Bridging the Gaps: Science Fiction in Nanotechnology." *Hyle* 10: 129-52.
- _____. 2008. "Nanotechnology: Legitimacy, Narrative and Emergent Technologies." *Sociology Compass* 2: 1-21.
- López, José Julián, and Ann Robertson. 2007. "Ethics or Politics? The Emergence of ELSI Discourse in Canada." *The Canadian Review of Sociology and Anthropology* 44 (2): 201-18.
- López, José Julián, and Janet Lunau. "ELSIfication in Canada: Legal Modes of Reasoning." *Science as Culture*. Forthcoming.
- M'charek, Amade. 2005. *The Human Genome Diversity Project*. Cambridge: Cambridge University Press.
- Moore, Kelly. 1996. "Organizing Integrity: American Science and the Creation of Public Interest Organizations, 1995-1975." *American Journal of Sociology* 101 (6): 1592-1627.
- Moran, Katy, Steven R. King, and Thomas J. Carlson. 2001. "Biodiversity Prospecting: Lessons and Prospects." *Annual Review of Anthropology* 30: 505-26.

- Morgan, Rhiannon. 2009. "Introduction: Human Rights Research and the Social Sciences." Pp. 1-22 in *Interpreting Human Rights: Social Science Perspectives*, edited by Rhiannon Morgan and Bryan S. Turner. London: Routledge.
- Nowotny, H., P. Scott and M. Gibbons. 2002. *Re-thinking Science*. Cambridge: Polity.
- Nundy, Samiran, M. Chir, and Chandra M. Gulhati. 2005. "A New Colonialism? — Conducting Clinical Trials in India." *New England Journal of Medicine* 325 (16): 1633-36.
- Parry, Browlyn. 2005. *Trading the Genome*. New York: Columbia University Press.
- Parsons, Talcott. 1949. *The Structure of Social Action*. New York: The Free Press.
- Pestre, Dominique. 2003. "Regimes of Knowledge Production in Society: Towards a More Political Reading." *Minerva* 41 (3): 245-61.
- Ravetz, Jerry. 2005. "The Post-Normal Science of Safety." Pp. 43-53 in *Science and Citizens*, edited by Melissa Leach, Ian Scoones, and Brian Wynne. London: Zed Books.
- Rothman, David. 2003. *Strangers at the Bedside*. New York: Aldine de Gruyter Books.
- Sell, Susan K. 2001. "Post-Trips Developments: The Tension between Commercial and Social Agendas in the Context of Intellectual Property." *Florida Journal of International Law* 195: 193-216.
- _____. 2003. *Private Power, Public Law: The Globalization of Intellectual Property Rights*. Cambridge: Cambridge University Press.
- Shiva, Vandana. 2000. *Stolen Harvest: The Hijacking of the Global Food Supply*. London: Zed Books.
- Somers, Margaret R., and Christopher N. J. Roberts. 2008. "Toward a New Sociology of Rights: A Genealogy of 'Buried Bodies' of Citizenship and Human Rights." *The Annual Review of Law and Social Science* 4: 385-425.
- Stevens, Tina. 2000. *Bioethics in America: Origins and Cultural Politics*. Baltimore: The John Hopkins University Press.
- Sunder Rajan, Kaushik. 2008. "Biocapital as an Emergence Form of Life: Speculations on the Figure of the Experimental Subject." Pp. 157-87 in *Biosocialities, Genetics and the Social Sciences*, edited by Carlos Novas and Sahra Gibbon. London and New York: Routledge.
- Thacker, Eugene. 2005. *The Global Genome: Biotechnology, Politics and Culture*. Cambridge, MA: The MIT Press.
- Turner, Bryan S. 2006. *Vulnerability and Human Rights*. University Park, Pennsylvania: The Pennsylvania State University Press.
- Woodiwiss, Anthony. 2005. *Human Rights*. London: Routledge.
- _____. 2009. "Taking the Sociology of Human Rights Seriously." Pp. 104-20 in *Interpreting Human Rights: Social Science Perspectives*, edited by Rhiannon Morgan and Bryan S. Turner. London: Routledge.

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