

*What is the collective (for)?  
Bioscience, exchange, and the politics of benefit-sharing*

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**Introduction: A research problem**

“Discoveries made with your DNA samples may be patented by us and the University. These patents may be sold or licensed, which could give a company the sole right to make and sell products or offer testing based on the discovery. Royalties may be paid to us, the University, and the Sponsor. It is not our intent to share any of these possible royalties with you.”

This marvelously assertive quote from a biomedical consent form is exhibit A in a recent article by U.S. bioethicists Jon Merz, David Magnus, Mildred Cho, and Arthur Caplan (2002), in which they argue that we are currently confronting a serious disconnect in the conduct of biomedical research. Prevailing regimes of consent (and recent legal precedent) in the U.S. and Europe affirm that people participate in the research process out of “altruism” (and that tissue samples donated or removed during treatment are a “gift” with no strings attached) while it becomes increasingly obvious, even in the way that consent is requested, that such gifts may well enable quite a lot of “property” and capital accumulation for researchers, companies, and universities. The rise of private tissue and biobanks in the U.S., Europe, and beyond has created enormous storehouses of biological matter (and bio-information) with great potential for generating commercial value, while the liberal interpretations of novelty and innovation that have prevailed in the United States Patent and Trademark Office since the 1980s have made the patenting of

genes and gene sequences (by companies and researchers) close to routine. The highly vexed and vexing question of whether or not the playing field should be leveled by giving patients, too, property rights in their own organs and tissue has come up in many a forum (see Cohen; Lock; Scheper-Hughes; Boyle for discussions). Perhaps the most well-known touchstone here (within the U.S.) is the John Moore case, in which the California Supreme Court ruled that Mr. Moore had every right to know that his doctors at UCLA might make a profit out of his spleen cells – but, denying his claim to a property right in his own organs, he did *not* have a right to a share of the proceeds. In this ruling and the long-prevailing research story underwriting it, research is, fundamentally, for the “good of humanity.” This sense of diffuse benefits, as we shall see further below, requires participation to be rendered as an act of gift-giving or donation, with no basis for a direct claim of “getting back.”

It is precisely this shaky and unsatisfying “post-Moore” consensus that Merz and colleagues target in their effort to show that we need to re-think how people should be gathered into the research process. They choose their quarry well: the epigraph above (which is their epigraph), is from a “protoypical” post-Moore consent form for DNA banking in genetics research, and it certainly gives pause. It also crystallizes a growing chorus of questions circulating in the world of bioscience and pharmaceutical research more broadly, in which the relationship between giving and getting is being fundamentally re-thought on many fronts (here I think of everything from bioprospecting contracts to efforts to promote generic drugs and “open-source” bioscience research and development). Merz and colleagues are among a growing number of bioethicists, policymakers, legal scholars, patient groups, and other critically involved parties who have recently, and vociferously, started calling for a new ethical principle, indeed a new research story -- one which seeks to exchange altruism for the novel principle of *benefit-sharing*. The idea, at its simplest, is that participants in research deserve some form of returns, precisely because their participation is leading to lucrative products for biotechnology, diagnostics, and pharmaceutical companies.

The rise of an ethic of benefit-sharing in clinical research intrigues me for a number of reasons. One of them has to do with its travels. As an explicitly redistributive idiom for bioscience research, “benefit-sharing” actually had its debut in the early 1990s in what might sound to be a rather different domain: in multilateral instruments regulating the management and commercial exploitation of biodiversity (plants, microbes, etc.) and “traditional” knowledge. Most pointedly, the 1992 UN Convention on Biological Diversity (CBD) provided a forum, a language, and a mandate (if a fragile one) that the industrial use of plants, microbes, traditional knowledge must come with a new promise of “equitable” returns for source countries and communities. It was in this context that I first became interested in how an extractive and hybrid scientific/corporate endeavor (collecting microbes and plants as leads for new drugs) has become refigured as a kind of ethical act in which drug-derived royalties would *come back* to source communities and nations in the form of compensation, funds for “economic development,” and technology transfer (see Hayden 2003).

Since the late 1990s, bioethicists and policy-makers working on guidelines for *clinical* research (such as clinical trials, research on human genetic disease, the management of blood, tissue, and stem cell banks) have become avid subscribers to this quasi-redistributive impulse as well. For the Human Genome Organization Ethics Committee, the architects of biobanks in Iceland, Sweden, and the U.K., UNESCO’s International Committee on Biotechnology, the U.S. President’s Task Force on Organ Donation, members of the University of Pennsylvania’s “Toward an Ethic of Benefits Sharing” project, and many others, the increasingly visible asymmetries of highly commercialized clinical research pose a problem in *this* domain as well. In view of the fortunes on the speculative horizon that may be derived from “human biologicals,” conventional ethical stories about altruistic research subjects and a diffuse common good are coming under more than the usual amount of fire. The idea of a more direct, traceable (re)distribution of the fruits of clinical research has been gaining ground here as well.

**Authorizing bioscience: from “speaking-for” to “giving back”**

There are certainly many things that differentiate these two domains of benefit-sharing discourse and practice. But there are also reasons to think them together. For benefit-sharing proponents, the story takes us down a twisted road of better and worse kinds of transactions of promises, bodily matter, and participatory labor. As an anthropologist of science, I see in these calls for benefit-sharing yet another story, one that has to do with the ways in which, to use a Foucaultian phrase via Nikolas Rose, bioscience's authority is itself "authorized" or legitimated (see Rose 1999). Bruno Latour's idiosyncratic language of science as (parliamentarian) politics gives us a different idiom for thinking about such authorizations. Latour argues that producing authoritative science is a process of literally gathering people and interests (and things) into research; in such gatherings-to, he argues, new publics and new collectives themselves take shape (see Latour 1993 and 2004).

Without doubt, bioethics –the practice, the discourse, the institutional arena --has become one of the more influential sites for gathering-to and brokering the legitimacy of bioscience research over the last forty years. This is particularly so when it comes to modes of research that explicitly and baldly *need* human participation: pharmaceutical trials, biobanks, clinical research of varying stripes. Here, to borrow a turn of phrase from Marilyn Strathern, there is presumably a world of difference between "including people" and "including them *well*" (ie, ensuring that their participation does not become a form of exploitation or mistreatment). And with shifts in the way that critical commentators understand "the contemporary research enterprise", understandings of what it means to include people well therein shift as well. Such changes in how people and their interests are gathered into the research process do not just authorize the research in question. Benefit-sharing proposals, I argue, are constituting *publics* in ways that demand a revised engagement from a science studies-ish point of view.

We do not have to look long to find examples of the ways in which science and publics take shape, together, in the sense that I am using the terms here. Consider the rather remarkable, Habermasian carnival of "public participation" that has surrounded

policymakers' efforts in the United Kingdom to grapple with and indeed legitimate controversial arenas of bioscience research, from *in vitro* fertilization (in the late 1980s), to cloning, stem cell research, and genetically modified crops at present. Insistently invoking a public that must be called into being in order to be consulted, researchers and policymakers have made recourse to a wide range of mechanisms, from parliamentary commissions, to focus groups, to public forums such as the 2003 "GM Nation?" debates, in order to take the public – or "society" – into account (see Strathern, Franklin, Liddell). The goal, in many instances, has been nothing less than the development of what European science studies scholars are calling "socially robust" research (Nowotny, Scott, and Gibbons 2001). Such efforts seem to offer all too literal an echo of Latour's notion of science as a form of representational politics: a process of *speaking for*, of designating spokespersons, of representing interests.

The rise of benefit-sharing matters to notions of science as politics precisely because of the ways in which its proponents are articulating a different kind of representational project– or perhaps more precisely stated, they are describing the representational functions, legitimating tropes, and obligations of biomedical research in distinctive ways (see also Hayden 2005). Here, we are not dealing exclusively with the Habermasian incitement to dialogue that is the warrant for exercises in public participation or even for renovated theories of informed consent– inclusion meaning dialogue, inclusion of different points of view – but something arguably quite different: inclusion figured explicitly as participation in processes of value production. What might it mean, both for bioscience and for our ideas about politics and publics more generally, to think of research not just as a mode of speaking for, but as a mode of giving back? More specifically, what and who are the biosciences' publics—*what kinds of political socialities must be called into being*—if research is to be reconfigured as something that can, indeed must, give back?

### **Takings and givings: pharmaceutical prospecting**

Let me start with a brief tale from the realm of bioprospecting. The 1992 UN Convention on Biological Diversity is perhaps the touchstone document/event in the recent history of benefit-sharing more broadly. Among other things, the CBD's novel mandate for benefit-sharing declared that plants, microbes, and "traditional knowledge" should no longer be considered part of the global commons and thus "free" for the taking. Rather, under the "voluntary" terms of the convention (which the United States has not ratified), these resources can now be subject to new kinds of claims-making by nations and communities of the global South. This soft law mandate has been articulated and elaborated upon in many ways: in professional society codes of conduct and indigenous community research charters, in national laws in "southern" nations, in a spate of benefit-sharing contracts themselves which have played out to often contradictory effect (Hayden 2003a and 2003b; Greene 2004), and in a series of follow-up conventions, including most prominently that which produced the Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilization (2002). The Bonn guidelines sought to put ten years of bioprospecting experience to good use in developing follow-up guidelines, making explicit, for example, that the Convention does not apply to human genetic resources; emphasizing the importance of prior informed consent for working with community resources; and laying out a more elaborate list of potential benefits, both monetary (such as access fees, up-front payments, and joint ownership of relevant intellectual property rights) and non-monetary (such as sharing of research and development results, collaboration in scientific research and development programs in the provider country, and institutional capacity-building).<sup>1</sup>

As we might imagine, over the last fifteen years or so, the questions of what precisely shall count as an equitable return (technology transfer, royalty payments, infrastructure building, community development projects?), how much would be considered equitable, and who shall be considered a benefit-recipient (national biodiversity institutes, some communities and not others, developing country scientists?)

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<sup>1</sup> Convention on Biological Diversity Decision VI/24, Access and benefit-sharing as related to genetic resources. Available at <http://www.biodiv.org/decisions/default.asp?m=cop-06&d=24>.

have been the stuff of intense controversy, contractual wrangling, experimentation, promise, and not a little bit of disappointment. And while many such negotiations take place at multilateral and national levels, a large part of the hashing-out has taken place in the practice of bioprospecting itself. I have written extensively about one particular prospecting initiative in Mexico, which ran under the auspices of the U.S. Government's ICBG (International Cooperative Biodiversity Groups) program.

Funded by the National Institutes of Health, the National Science Foundation, and, initially, the U.S. Agency for International Development, the ICBG program began in 1993 and has supported a wide range of benefit-sharing projects, all linking U.S. academic researchers to developing country collaborators on the one hand, and drug or biotechnology companies, on the other.<sup>2</sup> With this program, the NIH infuses a longstanding legacy of plant-based drug discovery with the language and mechanisms of sustainable development, hoping to link profits from pharmaceutical development to conservation and rural economic development (Schweitzer 1991; see also Reid et al 1993; Eisner and Beiring 1994; WRI et al 1993). As such, the ICBG belongs to the well-populated annals of 'market-mediated' conservation and development initiatives that took root in the late 1980s and early 1990s. In the agreement in question (the Latin America ICBG, for short), researchers in Chile, Argentina, and Mexico sent plant material or plant extracts to the US academic host, the University of Arizona, and to the US-based drug company Wyeth-Ayerst. If a drug were to emerge out of the pipeline an undisclosed percentage of royalties (reportedly 2-5%) would come back to Arizona. Just over half of that would then make its way to the appropriate source country, to be distributed among the relevant institutions and participating communities.

We might note, then, that the promise of actual benefits is an elusive one in the best of circumstances, but this is not the only register in which we might track the effects of benefit-sharing. The Mexican scientists with whom I worked made the point clear to me when they noted, in so many words, that now (following the CBD), you don't just

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<sup>2</sup> For information on the ICBG program see Timmerman 1997; Rosenthal 1997; and Grifo 1996.

collect plants anymore – you must collect the people who come with those plants (see Hayden 2003a). Long before any “benefits” even have a chance to trickle back, these scientists and their interlocutors must start to sort out the key questions for an ethic of benefit-sharing: on what basis shall people and their claims be attached to the inputs and outputs of “research”?

In Mexico, indigenous struggles over sovereignty, self-determination, and land rights—always a powerful question in contemporary Mexico—had intensified following the advent of the North American Free Trade Agreement (NAFTA) in 1994. There is still no national regulation in place regarding bioprospecting contracts – a detail to which many activists point when they say that in fact bioprospecting agreements are illegal by definition (see Nadal). But the lack of national regulation has certainly not been prohibitive; Mexico has been home, since the early 1990s, to a wide range of bioprospecting agreements, involving various configurations of participating agencies, institutions, and local interlocutors, and using a variety of models for gathering participants and would-be benefit-recipients into the fold.

In this agreement, the NIH, for its part, had a seemingly straightforward sense of who should count as a benefit-recipient: in order to both reward and encourage local stewardship of biodiversity, Latin American scientists were supposed to sign contracts with the people who provided them with plants/information. It sounds simple enough: you give, you get back. We might note, though, that for this equation to work, the NIH requires something quite complicated and elusive on the ground: a research site that contains, all in one package, plants, knowledge, people, territory, and decision-making authority, congealed in the name of the participating community.

The Mexican ethnobotanists implementing this agreement wreaked considerable havoc with this plan of direct, contract-mediated exchange with something called communities. In fact the lead ethnobotanist, Robert Bye, culled the majority of his initial plant samples from other sites altogether –most notably, from urban market-places. And urban plant vendors, one ethnobotanist told me, are merely “vectors of transmission”.



They are not *sources* of knowledge and thus don't merit royalty payments. These scientists were pointedly not asking the people who provide them with plants and knowledge to sign off as their future benefit-recipients.

What they have done is negotiate benefit-sharing relations in parallel, with a range of indigenous communities and organizations, including a group of traditional healers who wanted to start an ethnobotanical garden in Oaxaca, and an organic bean cultivation project in the Sierra Tarahumara in Chihuahua. These are the groups to whom future royalties would be directed. The scientists explained their strategy to me, as well as to their funders in the U.S., in part in terms of the cosmopolitan nature of medicinal plants and knowledge about their use in Mexico: they are well-traveled, hybridized resources. Thus, much to the NIH's discomfort, they argued that it is counterproductive to try and trace benefit-sharing claims back to one bounded community: medicinal plants, they argued, simply don't work that way in Mexico.

Program administrators at the NIH found this detour around the notion of community unsettling for a few reasons, not least of which is that market collections seemed politically dangerous. Why? Precisely because they do not come with contract-signing benefit-sharing recipients attached. Plant collecting figured as a commodity transaction, they argued, left the project uncovered in quasi-judicial terms. This assessment, both understandably and slightly ironically, came in the aftermath of a massive international controversy around a second ICBG project in Mexico, which much more closely replicated the NIH's view of the ideal relation between plants-collected and benefits-promised. But in that case, a team of US ethnobotanists' plan to work directly with Mayan communities in Chiapas ran seriously afoul of local, national, and international sensibilities. At stake, very directly for the involved communities in Chiapas, were powerful conflicts over dominion, decision-making authority, and the question of who has the right to broker access to these ethical appropriations. The NIH ended up cancelling the Chiapas project altogether in 2000 (see Brown 2004). And, smarting a bit from the controversy, the ICBG project director insisted to Bye that he

*cease* his market work altogether and work *exclusively* with “contract-signing communities.”

This strategy might not make much sense outside of an understanding that community – figured as a bundle of plants, knowledge, territory, and political authority -- was the NIH’s only hoped-for guarantee that collections were proceeding with at least a gesture towards authorization in a context in which regulatory authority and territorial/intellectual dominions are hotly contested. In this particular articulation of benefit-sharing, resources had to be actively embedded in community *so that* they might (then) be appropriated -- *well*. It is in this sense that an idea of “community” became what we might call a site and mode of conversion: not just in the Marxian sense of releasing value (see Joseph 2002), but also, simultaneously, as the form of political sociality which could turn a taking into something that could give back.

Though the details might take some odd turns, it is perhaps not surprising to find the idea of community doing such hard work in the context of bioprospecting initiatives that take as their subjects and objects indigenous peoples, medicinal plants, and something called ‘traditional knowledge,’ in a place like Mexico. But I want to argue that a particular notion of community – or something very much like it (a deliberately loaded phrase) – is absolutely necessary to the idiom of benefit-sharing more broadly. Let me explain, with an eye now on clinical and genetic research.

### **Benefit-sharing: clinical research and genetic databases**

In the late 1990s, patient groups in the U.S., among other actors, started elaborating some proposals of their own for re-formulating the economies of participation and profit in clinical research. Genetics research in particular has spawned groups and foundations which are playing an incredibly active role in facilitating research, with patient groups themselves often funding studies, recruiting participants, creating DNA banks, and enrolling tissue and blood donors (see Rapp, Heath, and Taussig; Rabinow French DNA). With such active participation in mind, families affected by genetic conditions such as Canavan’s disease and PXE have also been making concrete demands

on the end-results of this research. Demanding guaranteed access to resulting medicines, filing lawsuits to liberate resulting diagnostic tests from overly restrictive patents, and using Material Transfer Agreements to have some say in the “downstream” use of research results -- these actions seem reasonable, fair, even dare we say, ethical. But they are also potentially troubling to the very bioethical principles and thus to the protocols that hospitals, universities, and clinics have conventionally used for much of the last half-century to authorize research and the recruitment of participants.

Why? Consider one of the key mechanisms in post-war bioethical conventions for protecting research subjects from coercion: the foundational prohibition against “undue inducement” – luring people, however indirectly, to participate in research by offering (too many) direct returns on their involvement. For example, it is standard practice (though not starkly codified) in the U.S. to offer clinical trial participants “reimbursement” for their time and travel, but not to pay them above this token or nominal fee, as such payment could conceivably render the trial illegitimate. International conventions are more explicit: the Human Genome Organization (HUGO) Ethics Committee wrote in 1996 that “[u]ndue inducement through compensation for individual participants, families, and populations should be prohibited” (in Knoppers 1999: 24); the Council of Europe decreed in 1990 that financial benefit for research in general should be considered an “inducement which compromises free consent” (in Knoppers 1999: 24).

Needless to say, the vagaries of (un)due returns, the definition of “genuine” voluntarism, and the boundaries of inducement have hardly been stamped out by such principled clarity. At the very least, we might point to the fact that participation in clinical trials is often the only way to gain access to experimental or otherwise unavailable treatment. HIV/AIDS activists in the U.S. made this point exceedingly clear in the late 1980s and early 1990s (see Epstein 1998), and the argument is currently placed in high relief in the context of controversies over clinical trials in the developing world (John LeCarré’s *The Constant Gardener* doesn’t hedge on this point). Clinical research is

always, arguably, an exchange in some fashion or another. Nonetheless, in post-war biomedical research, the “for whom” question has, *rhetorically* and *ideologically*, been farmed out into the future, and into an undifferentiated sphere of public good: participation has been regulated in U.S. and European biomedical circuits as a *gift to strangers*. But this mode of including people fairly, or of precluding exploitation of research subjects, is now increasingly seen as a potential source of injustice. As we saw at the outset of this paper, research participants’ constitutive exclusion from access to the vast profits that accrue to researchers and companies is, it would seem, growing difficult to defend and describe in conventional ethical languages of gift and the public good.

The forms of patient activism I mentioned above have registered, in both word and deed, a substantial challenge to the notion of the gift as the founding gesture of participation. And these activists’ bioethical advocates have been struggling to catch up: that is, to rewrite the narrative – and thus the institutional protocols-- of how to include people in research, and include them well in these transformed conditions. Many of them are, in fact, looking “laterally” to the world of bioprospecting. Consider this assessment from European bioethics scholar Kare Berg: just as “there is an almost universal feeling that rich countries should not exploit poor countries’ [flora and fauna . . . , so too would there exist] a state of unfairness if research on genes in a family led to marketable products and revenues for the pharmaceutical industry, unless the family was given something back” (Berg 2001: 240). The lovely naivete about universal feelings on the matter of North-South relations certainly stand out, but there is something more important on display here: the not-inconsequential third worldification of the first world research subject. Where benefit-sharing in the domain of bioprospecting started from the recognition that bioscience is a kind of resource extraction that might now be made “ethical” or equitable, here, we might pause to take note of the fact that previously “ethical” research is now being recoded as a form of asymmetrical resource extraction. As we shall see below, this does interesting things for a notion of the subjects of benefit-sharing.

Seeking to address this problem of asymmetrical exchange and the specter of exploitation in human genetics research, the Human Genome Organization (HUGO) Ethics Committee drafted their own Statement on Benefit-Sharing in 2000, which laid out six wide-ranging principles meant to stimulate discussion and to elicit further elaboration. These principles range from the diffuse insistence “that all humanity share in, and have access to, the benefits of genetic research” (recommendation 1), to the slightly more concrete notion that “benefits not be limited to those individuals who participated in such research” (recommendation 2), to the proposition, mirroring the entrenched figures long bandied about in the world of bioprospecting, “that profit-making entities dedicate a percentage (e.g. 1% - 3%) of their annual net profit to healthcare infrastructure and/or to humanitarian efforts” (point 6) (HUGO Ethics Committee 2000; see Parry [ ]).

A team of bioethicists based primarily at the University of Pennsylvania, working with Canavan Disease and PxE (Pseudoxanthoma Elasticum) family groups, has taken up the suggestion to develop a more specific set of proposals, and to elaborate the philosophy on which a new research relationship might be forged. In the 2002 article “Protecting Subjects’ Interests in Genetics Research” which provided my opening in this essay, Jon Merz, Mildred Cho, David Magnus, and Arthur Caplan write:

We believe it is unacceptable to presume that patients, subjects, disease-associated advocacy groups, foundations, and government (and in turn, taxpayers) are all pure altruists, as policies and practices now do presume, especially when these stakeholders have contributed in a meaningful way to the research enterprise... we believe there has been a market failure with respect to the value added to the research enterprise by patient and subject groups, and ways should be found to recognize and reward their contributions (2002: 969).

But, we might pose, again, the logistical-theoretical question, in what idiom shall people and their claims be attached to the inputs and outputs of “research”? Merz and colleagues lay out a range of possible forms of benefits: they reiterate the demands made by Canavan Disease and PxE activists (such as requesting that resulting diagnostics or treatments be

made available to the affected/participating groups at a reasonable price); they nod in the direction of the HUGO statement's proposals though they note, pointedly, that the 1-3% figure is arbitrary and "does not reflect any economic analysis of relative contribution or fairness" (969); they give hedging support to the idea of royalty-distribution --as long as it does not inflate prices downstream (968-969); and they suggest a few ideas of their own, such as issuing a single share of "subject-class" stock in any tied-in biotech venture to all participants in a research trial. The stock may end up being worth a great deal, but it may be worth nothing at all (the possibility that it might be worthless presumably saves them from the specter of undue inducement) (969).

But in this thicket of potential remedies, they are also incredibly clear about how *not* to recognize and reward participant interests. After making very clear that the source of the problem at hand is to be found in the market, they draw their line about where the solution resides: "The claims made herein about benefits sharing are based purely in equity and not property or other rights; to put it simply, we believe it is the right thing to do" (Merz, Magnus, Cho, and Caplan 2002: 970). This rather striking investment in equity rather than legal rights is absolutely crucial to the story I want to tell here, and it is by no means exclusive to the Upenn team's particular articulation.

Benefit-sharing proposals in clinical research, as with bioprospecting, operate comfortably in the idiom of intellectual property --valuing contributions to innovation, and rewarding participation in the Lockean project of adding labor to nature. But they routinely stop short of offering property rights as a kind of benefit itself. Indeed Shane Greene's work on an ICBG prospecting collaboration in Peru gives us the exception that proves the rule in that arena: Aguaruna groups involved in that project were able to negotiate a "know-how" license with the participating company. It was a short-lived achievement of "indigenous intellectual property rights" (the company declined to renew the arrangement at the first opportunity) that stands out as unique in contemporary bioprospecting arrangements. It is much more common, indeed, to find recourse to a wide range of other idioms of return: donation, incentive, up-front payments or access

fees, technology transfer that do not require/assume/produce “rights” claims (see Hayden 2003a). Careful to reaffirm the right of firms to accumulate intellectual property claims on biologicals and their derivatives, the UPenn discussion and many others like it desperately want to avoid what seems to be their Hayekian nightmare, and indeed the solution towards which John Moore himself was heading: an open market in kidneys and spleen tissue; the prospect of indigenous patents or copyright (see Michael Brown 1998); property rights for each of us in our own DNA and organs; plant collection, indeed, as a commodity transaction. In the words of my colleague Marc Stears, “marketization all the way down” is the specter that haunts benefit-sharing -- the UPenn team’s articulation thereof, the NIH’s prospecting program, and many others as well (Stears, pers. comm. 2004). It is significant that a fair number of patient groups and indigenous communities do not share this aversion and, as we have seen, have made much stronger claims, precisely in the language of rights.

But my purpose for the moment is not to argue that investing “us” all with rights in our bits is the way forward here. I am, rather, interested in the effects of the insistent disavowal of rights on the part of benefit-sharing proponents. I am interested, in other words, in how bioethicists’ and policy-makers’ aversion to investing research participants in rights requires, at least strongly requests, benefit-sharing’s publics to take a particular form.

### **What is the collective, and what is it for?**

Collectivization: I use the term advisedly (perhaps, given its resonances from the early 20<sup>th</sup> century, ill-advisedly). But I have in mind a number of developments in genetics and bioscience research which are crucial to understanding the form that benefit-sharing proposals are taking. For it is not just the old staple of altruism which seems to be taking a slightly incoherent hit at the hands of “the market” and its failures. Out with this principle goes its principle actor – the instrumentalized, autonomous individual – and in comes something/someone else: the collectivity as sovereign ethical subject.

Benefit-sharing discussions have emerged in the context not just of the increasing commercialization of biomedical research, but also in the context of increasingly well-established critiques of the autonomous individual as the only thinkable, actionable subject of bioethics. Medical anthropologists such as Arthur Kleinman, communitarian ethicists such as Daniel Callahan and Michael Parker, and feminist ethicists such as Susan Wolf, to name only a few, have been at the forefront of more than a decade of powerful challenges to this model from within the field itself, as well as from its margins, to use Kleinman's place-marker [citations]. Their critiques have often focused on processes of decision-making, drawing on communitarian political theory and a Habermasian notion of communicative rationality as they call for a more *relational* and dialogical notion of the ethical subject.

Genetic research in particular has given a sense of urgency and a particular shape to such efforts to place collective subjects at the heart of research protocols' processes of consent. For many critical commentators, at stake is simply a newly salient empirical reality: due to the (shared) nature of genetic material and the information it provides, families, disease communities, populations or "ethnic groups", even entire nations (such as Iceland, Estonia, the UK – all of which have established national "biobanks") are the subjects of genetics research and thus must be recognized as those who grant consent. (As a longstanding student of feminist kinship theory within anthropology, I refuse to concede the definition of genetically-defined groups as so blindingly obvious, but that is a point for another forum (see Palsson on the definition of *the* Icelandic gene pool)). Montreal-based ethicist Bartha Maria Knoppers, chair of the Human Genome Organization (HUGO) Ethics Committee and a vocal advocate of benefit-sharing in genetics research, noted in 1999 that progress was being made in the recognition of group subjects, and that more and more international organizations were by that time recognizing, at least, that "genetic information is by its very nature familial" (Knoppers 1999: 23). Stanford legal scholar Henry Greely argued forcefully in 1997 that U.S. bioethics' historical emphasis on individual informed consent is simply inadequate for a



kind of research - human genetics – that “is almost always about *groups* of people... -- ethnic groups, disease organizations, and families” (Greely 1997: 1399, emphasis in the original).

These arguments have permeated extended discussions of – and experiments in -- the collectivization of the research subject, in which the notion of “community” as a protectable collective has been ricocheting vigorously between the aboriginal and the associational, the conceptual spaces of the 4<sup>th</sup> and 1<sup>st</sup> worlds, ethnic groups and patient groups, nations and families. Arguably among the most powerful and visible of the structures devised for community consent have been protocols for indigenous and aboriginal groups such as those developed for the controversial Human Genome Diversity Project (HGDP), which is the context in which Henry Greely, quoted above, was writing (Greely 1997; Reardon CITE). As Greely and a number of his colleagues on the North American Regional Committee of the HGDP noted, their model protocol was needed to deal with “the ethical and legal issues that are raised when a project seeks DNA explicitly from populations, not individuals, especially when those populations may be scientifically unsophisticated and politically vulnerable” (North American Regional Committee of the Human Genome Diversity Project 1997: 1433).

With the HGDP’s models of community consent firmly in mind – and institutionalized--, the notion of the consenting community is now being actively borrowed “back” from the aboriginal or the indigenous. In Canada and Australia, two nations rather famously committed to their own brands of liberal multiculturalism (see Povinelli 2002 on the politics of recognition in Australia), a growing interest in community consent for clinical research more broadly has prompted several efforts to explore whether the bioethical protocols developed specifically for indigenous or aboriginal communities might be applicable to other, “non-aboriginal” collectives, such as Ashkenazi Jews, people with HIV or with breast cancer, or other epidemiologically- or genetically-defined populations. Such proposed borrowings provoke some serious definitional quandaries, to be sure. What, in the end, is a (protectable) collective?

In a 1999 review of these Canadian and Australian borrowings, Halifax-based bioethicist Charles Weijer (who has been very active and visible in efforts to develop protocols for “protecting communities in research”) and two of his colleagues noted that this loan does indeed face some serious challenges. Drawing from the skeleton-laden anthropological closet, Weijer and colleagues wrote, “[a]boriginal communities tend to be geographically localized, bound by shared histories, cultural traditions, languages... But other communities lack these morally relevant features ....“ (Weijer, Goldsand, and Emanuel 1999 XXX). What *does* promise to bridge the gap, in their assessment, is the question of governance: “if one is to be able to implement the requirement for community consent ..., then the community in question *must* have a system of legitimate political representation.” [1999: xxx].

Echoing and arguably renovating processes readily visible in the histories of colonialism, development, and bioprospecting (see Greene 2003; Hayden 2003), the vexed question of what community *is* thus dissolves into the much more streamlined question of what community *does*. And this formulation proves central to my central question, who is the subject of benefit-sharing? The answer suggests that Latour’s notion of (bio)science as a mode of speaking-for has not been superceded in any simple sense: it has been intensified and given a new burden. Here are Jon Merz and colleagues, again, speaking from their work with PxE and Canavan’s disease patient activist groups in the U.S.:

Unless there is a group that represents participants, there may be no good way to recognize and reward individuals’ contributions ... Advocacy groups thus serve two functions: adding value by facilitating research and providing a collective voice to individual participants, backed by the power to negotiate and frame the ways in which research and commercialization take place [Merz et al, 2002: 970].

I want to make a blunt argument, drawing from these equally blunt assessments of who/ what benefit-sharing requires. In efforts to re-authorize bioscience participation as an act that exceeds the gift but that cannot proceed, unleashed and unchaperoned, directly to

market, benefit-sharing proposals in this domain, too, need something like “community.” As ever, returns require a destination. And in the matter of giving-back in clinical or genetics research, the individual is a nervous-making entity: a conduit to the idiom of property rights, to commodity exchange, to “undue inducement.” Its disavowal takes us swervingly, *necessarily*, to the –a—collective. What are the implications of such acts of collectivization?

I opened this essay by asking about the kinds of political sociality being called into being in order to re-authorize bioscience research as something that can “give back.” The answer seems clearly or at least insistently, to be “community” or the collective. But with this answer, something else has become perhaps less clear. What does this answer tell us about the kind of entitlement that benefit-sharing is meant to be?

### **A form of exchange, betwixt and between**

A long tradition of social and political theory tells us very clearly that, despite the insistent move on the part of many benefit-sharing proponents (not rights, not property, therefore community), “community” and “rights” or “community” and “commodity exchange” are anything but mutually exclusive (see Joseph 2002). Indeed we could look to communitarian political philosophy to think about the notion of collective rights, or to Miranda Joseph’s argument that “community” is necessary to rather than external to “capital” , in order to think about these notions as mutually constitutive. But longstanding conversations in anthropology and economic theory also affirm just how persistent these oppositions have been in what Marilyn Strathern calls a “western metaphysics” around questions of exchange: the undying gift/commodity question that so powerfully animates these discussions about the benefits of research carries with it dense (and always arguable) associations and negations— if not alienable commodity, then inalienable gift; if not market-based transactions between abstract individuals, then connected forms of “reciprocity” mediated by groups or communities (Mauss; Gregory; Gudeman; Strathern 1988; Scott 1976).

But of course the intriguing swerve *here*, with the question of benefit-sharing, is precisely that we are not in the “old” terrain of gift versus commodity, or a capitalist economy versus a moral economy, but in something else, which we might have to call not-gift versus not-commodity. In all of these discussions, benefit-sharing is both a problem and a solution that dwells in the interstices of a familiar grid of imaginable actors and—correspondingly -- imaginable forms of transaction. Thus for example Stanford lawyer Henry Greely, in his efforts to address the question of community protocols for the Human Genome Diversity Project, identified the problem as one of protecting the “groups between”: that is, research subjects (groups, populations, families) who, because they are neither individuals *nor governments* (ie, the state), tended to be unassimilable to conventional U.S. bioethical protocols (Greely 1997: XXXX).

And as we’ve seen, it is not simply the “groups” that are “between.” The kind of exchange that benefit-sharing is imagined to be also falls under this moniker. For bioethicists and policymakers advancing proposals for benefit-sharing, community-as-group *grounds* a kind of exchange that explicitly and deliberately remains betwixt and between. “Neither Moore nor market,” in legal scholar Charlotte Harrison’s fortuitous phrase (Harrison 2002), benefit-sharing is a form of downstream redistribution framed precariously, nervously, in the space between (not-) rights and “what is right.”

### **Distributive agency: from the ‘for whom?’ question to the ‘by whom?’ question**

Postcolonial theorist Achille Mbembe and Mexican economist Julio Bolitvinik (among others), draw our attention to the precarious space between “not-rights” and “what is right” when they talk about “transfers” – by which they explicitly mean the distribution and allocation of resources and entitlements when political subjectivities are unmoored from the forms of citizenship and rights so dear to liberal political theory. Mbembe was writing of postcolonial Francophone Africa, and Bolitvinik, of political trends in contemporary Mexico which, he argues, have made the “proper person” a receiver of transfers rather than a subject of rights. [citations] Transfers, allocations, distributions: these are words that take us out of the artificially isolated spheres of market

and exchange, gift and commodity, and remind us that the sharing of benefits is simultaneously, necessarily, an idiom of politics, of social contracts, of vexed traditions of thinking about “the state,” too, as that which performs and regulates acts of taking and acts of giving-back.<sup>3</sup>

What then if we think about the rise of benefit-sharing and the death of altruism as a second kind of story, not just about (unequal) exchange and commercialization but also as a story about broader infrastructures of distribution and redistribution? The designated high priest of post-war British social policy, Richard Titmuss, certainly would have done so. In fact we might argue that he has already done so, in his study of the British voluntary blood donation system, *The Gift Relationship: From Human Blood to Social Policy*, published in 1973. Titmuss’ markedly anthropological question, invoking Durkheim, Mauss, and Lévi-Strauss, was none other than, “why do people give to strangers?” Unlike the latter-day and primarily U.S.-based ethicists on whose work I’ve been drawing to talk about genetic benefit-sharing, Titmuss left no room for doubt that a blood donation system based on altruism was *necessarily* a story about the state. It was in the context of the National Health Service in particular, Titmuss argued, that the British blood donor donated, and the research participant participated, with no expectation of direct reward. Ideas of altruism may have been calibrated to ideas of *individual* motivations and interests (or lack thereof), but Titmuss argued that the “right to give” depended absolutely on the existence of a wider community – one, in this case, cared for (and taxed by) the state, and holding a strong commitment to universal health care, “free” as Tony Blair and much of New Labour still insists, “at the point of delivery.” In Titmuss’s view, altruism could be the glue that held this society – and one, very influential, post-war biomedical research story -- together, precisely because the

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<sup>3</sup> We might take note of something that research relations figured in the name of benefit-sharing and those figured in the name of altruism have in common: they both refuse an exchange between individuals in favor of a more diffuse, collectivized exchange. In both cases, to echo an observation made by Marshall Sahlins in a rather different context, the distribution of the benefits of research might be seen not as a question of reciprocity, but as a form of redistribution. The difference for Sahlins lies in the agent responsible for the giving-back: reciprocity, he argued, is enacted between individuals, while redistribution is an act that falls to a representative of some kind of political authority. The question, in the end, is who and what takes responsibility for these (re)distributions.

collective, the public, held a certain value (Stears, pers. comm. 2004). Not surprisingly, the U.S. and its highly privatized health care infrastructure was the explicit Other in Titmuss's story. He wrote his passionate defense of a social state that must protect the "right to give" precisely at a moment when the U.K. was contemplating the americanization of its blood donation system – i.e., paying donors to give blood.

I invoke Titmuss here for a few reasons. It is not my point simply to argue that "altruism" is a story that had significant traction in early 1970s Britain and that does not in the late 1990s U.S.<sup>4</sup> These suggestive contrasts between the U.S. and the U.K. do more than serve as place-holders for an argument that things were different *then*, and/or that things are different *there* (see Tutton 2003). Invoking Titmuss also reminds us that there are multiple ways of telling the contemporary benefit-sharing story, of embedding it, or of asking: what is the problem to which benefit-sharing is the ostensible answer? Taking a cue from Titmuss and the ongoing conversations of which his notion of the gift is a part, I want to argue that we can choose to make benefit-sharing a problem about broader questions of distributive agency, rather than one that is narrowly focused on skewed ledgers of atomized interests, badly or better- recognized.

### **Cutting collectives (I)**

What would happen, then, if we followed Titmuss's lead and made "genetic benefit-sharing" in the realm of clinical research, at least, a question about health care systems and the duties/rights of *the* collective? Legal scholar Charlotte Harrison, writing of the U.S., where the social state in the U.K. sense has not been much in evidence for the last fifty years, does just that when she points out that the visions of benefit-sharing that we see most clearly in this country seem simply to reward those relatively few groups

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<sup>4</sup> The difference between Titmuss's language of the right to give and the social state of *his* 1973 Britain, and Merz, Kaplan, Cho, and Magnus's portrait of stakeholding participants in the research enterprise of *their* late 1990s United States, could not be more stark. And, instructively, sociologist Richard Tutton has shown that the U.K.'s primary bioethical gatekeeping institutions (specifically, the Nuffield Council and the Medical Research Council) make ample recourse to Titmuss's notions of gift, altruism, and now, *genetic* solidarity in their discussions of what to do with the vexed question of giving and getting where human tissue banks are concerned (Tutton 2003). Here, it is Tutton who is left to voice some skepticism about the efficacy of these institutions' calls for a renewed sense of research as a "social contract"; these institutions' commitment to solidarity, he argues, reproduces a rather entrenched template of who can --and who cannot-- derive profit from human tissue. We are back on familiar ground, then.

who are best able to make demands. In her 2002 article in the American Journal of Law and Medicine, Harrison looks warily at the growing trend in the U.S. in which some patient groups or families have begun to bargain with (or sue) researchers over rights and rewards. She notes pointedly, “The current state of affairs presents some of the least attractive features of a new and uncivilized frontier .... [T]he failure to develop a social policy for the many is mitigated only by the self-help of the few – in particular, those few who are fittest for bargaining or litigation” (Harrison 2002: 81).

Following this critique, does benefit-sharing in the realm of clinical research and health care simply “cut the collective” into fragments, privatize redistribution, and, in the process of enabling benefits for some, shirk a public or collective responsibility to develop a social policy for caring for the many? With my eye firmly on the U.Penn and Stanford bioethicists’ vision of patients as stakeholding contributors to processes of value production, I would answer yes, without doubt. Proposals advancing an ethic of benefit-sharing inarguably *do* draw our attention to a disconnect. But in my view, what is starkly on display is not (as Merz and colleagues would have it) the poverty of the isolated principle of “altruism” per se, but the impoverishment of the political and social infrastructures that once made altruism thinkable – and made it a once viable narrative thread in certain research stories. When *that* way of asking the “for whom?” question seems to lay bare an injustice, we start hearing calls for the benefits of research to be recalibrated—both extended to newly particular configurations of “community” and thus, inescapably, gathered back to some participants and not others. There are no strangers in this vision, only fellow (and competing) stakeholders.

### **Cutting collectives (II)**

*And yet ...* As with most such laments, we must ask a few questions about the kind of entity we suppose “the state” or “the collective” to be when we mourn its fragmentation this way. A cohesive Durkheimian notion of the social very explicitly (and many argue, romantically) underwrote the notion of the collective which, in Titmuss’s view, enabled the now-embattled principle of altruism to *work*. To draw out a different

set of implications for the questions of collectivization at work through benefit-sharing, I want to gesture towards a rather different notion of the collective, one that I draw (advisedly) from Bruno Latour in his recent efforts to lay out his theory of a democracy that speaks not just for humans but for nature and non-humans..<sup>5</sup> While I am not working towards a Latourian parliament of things, what *is* of use to me are the theoretical legacies from which he draws, and the idiom of *collecting* to which they lead. Invoking the more open-ended notion of a sociology of “association” drawn from Gabriel Tarde as well as the pragmatism of John Dewey, Latour defines his collective thus: “In spite of its use in the singular, the term refers not to an already-established unit but to a *procedure for collecting associations ...*” (2004: 238, emphasis added). For Latour (or more to the point, for Tarde and Dewey), the social and the public are idioms for thinking about collectives that come into being in response to particular kinds of conditions, or in Dewey’s sense, to shared “matters of concern“ (see Dewey 1927; Latour 2004).

It is with such contingency in mind that I would propose that we think about benefit-sharing as a process of *cutting collectives* in a second way. That is, I do not simply mean chopping up an existing whole (my better analytic instincts notwithstanding, I am loathe to dismiss that argument outright), but literally making or constituting collective entities too; that is, drawing people into association by gathering them (*well*, adequately, ethically) into the research process. Thus we might recall that Merz and colleagues argue that benefit-sharing is a mode of representing interests, and that there is no adequate way to properly represent individuals’ interests except in the form of advocacy groups. Their call is not just to recognize but, they imply, to form the groups that can represent individual patients’ interests. As such the argument advanced by Merz and colleagues —somewhat despite itself, I would note—strays from the “just the (genetic) facts ma’am” notion that these groups and their interests are already given, and reminds us instead that such collectives and their interests also come into being in their articulation with “the research enterprise.” I have made an analogous argument with

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<sup>5</sup> Latour’s project is to make a space for humans *and* non-humans, the social and the natural, in his vision of a new collective, and such interminglings are not part of my analytic project in this essay.



regard to bioprospecting and the models of development on which it draws (see Hayden 2003a and 2003b), and I would extend it here as well. Suggestions for re-authorizing participation in research as a process of benefit-sharing literally call for the constitution of new collectives –new representative and distributive agencies.

In fact, there a number of thoughtful proposals circulating in the worlds of law and ethics in the U.S. and abroad, many of which are directly or indirectly critical of the kind of stakeholding language we find in the U.Penn benefit-sharing proposals, but that also respond to the problem of how to make bioscience *give back* by creating new collective agencies. In her proposed model for compensating tissue donors (again, “neither Moore nor market”), Charlotte Harrison eschews property law and instead turns to liability rules and tort law, which are used to mediate such things as worker’s compensation claims. Liability, she argues, can ground a better redistributive project in large part because the terms are decided upon and administered collectively or publicly (that is, by government agencies and elected legislators rather than through private contracts) (Harrison 2002). Following Carol Rose, she argues that liability takes something that might be “ethically problematic” when conducted “in private” and places it in the realm of that which is publicly mediated – out of the bioethical, and into the political, we might add. Or consider the “charitable trust” model proposed by lawyer and STS scholar David Winickoff and physician Richard Winickoff, as an alternative mode of governance for tissue banks which are currently proliferating in the private sector in the U.S. and more broadly. In this model, donors would sign over their tissue samples not to a private biobank but rather to a charitable trust in which the “general public acts as the beneficiary.” The trust model would thus create a fiduciary rather than property relation between a donor and biobanking institutions, and would enjoin hospitals, for example, to act as “custodians” rather than “brokers” of donated tissue (Winickoff and Winickoff 2003).

Liability rules mediated by government tribunals, collective bargaining effected by genetic disease advocacy groups, charitable trusts grounded on fiduciary relations....

the question of how to recalibrate takings and givings in the domain of bioscience has generated an intriguing array of imagined collectives, designed to take charge of projects of redistribution, grounded in a critique of the gift and a refusal of property, and requiring the creation of representative agencies which are, *by definition*, both “collective” and collectives. The proliferation of collectives – or imagined forms thereof-- that accompany calls to turn bioscience into a relation that can (must) “give back” intrigues me. With the declared death of an “old” language of the collective – altruism, overseen by the (welfare) state – bioscience research becomes a site for the proliferation of other idioms of the public, of collectives, of community, and even of collective bargaining. Why does bioscience and its newly problematic status as a site of intense capital accumulation provoke such a riot of collectivization?

### **Benefit-sharing as risk-sharing**

I have entertained a few possible characterizations of benefit-sharing, from a renovated form of exchange to an experimental form of political and distributive agency. I might also note a third way of thinking about this new idiom benefit-sharing, which I mentioned in passing earlier. Like corporate social responsibility, the privatization of social security and health care, and other neoliberal projects that have taken hold across Latin America, the U.K., and the U.S. (and elsewhere), benefit-sharing is also, foundationally, a form of risk-sharing. In many of its manifestations, it privatizes and segments project of distribution and allocation. And insofar as the production of “benefits” depends on a profitable product, it exposes such allocations to the fickleness of pharmaceutical and biotech markets. I mentioned, above, that we might think about this in terms of the question of health and the rights of the ‘many’ versus the entitlements of the few. But it is a matter that comes into play in the arena of bioprospecting as well. For benefit-sharing agreements have literally come in as a prospective source of community development funds precisely where, as in Mexico, free trade agreements have done away with the “old” forms of state subsidies for rural producers. This may sound quite speculative but the connections are, at times, stunningly literal. For example, the

groups that UNAM ethnobotanist Robert Bye chose as some of his potential benefit-recipients in the bioprospecting agreement I have studied were organizations that had first been established through a Salinas-era government program (Solidarity) meant to soften the blow of NAFTA in the early 1990s. When these government funds dried up, the Latin America ICBG bioprospecting program literally stepped into the breach, as Bye hoped to use prospecting project funds and future benefits to rejuvenate some of these small-scale enterprises (among which were an artisans' enterprise in Sonora, using sustainably harvested wood). It is of no small consequence that this latter prospecting project, like the majority of bioprospecting projects with which I am familiar (and like the government project which preceded it), has not generated substantial benefits to speak of and was in fact canceled in the fall of 2003, before any pharmaceutical products came close to hitting the market.

I will end, then, with necessary note on failure. I have been talking here about the productivity of an idiom—a reconfiguration of bioscience as something that must give back, and that in order to do so, must produce its publics, its participants, in a particular way. Does it matter to my story that in its own, markedly problematic terms— as a facilitator of new kinds of giving-back— benefit-sharing is already, in many ways, a failed idiom? I say this with an eye on over ten years of bioprospecting experiments in which the promised sharing of benefits has proven a notably ineffectual facilitator of new kinds of “downstream” redistributions.

The failure and indeed the constitutive impossibility of benefit-sharing is, in large part, what fascinates me, and what makes me take note of its remarkable resonance, its proliferation across domains, and its presence not just in vague declarations of good practice but in the actual reconfiguration of research relationships. As I've argued in my work on bioprospecting, benefit-sharing is not simply the downstream supplement its architects hope it will be --that is, an added-on act of giving back that leaves the rest of the research process largely intact. In fact it rarely materializes as such, and often seems to do exactly the opposite. For, in the act of naming future benefits and future benefit-

recipients, researchers, their funders, and their interlocutors must and do adjust their relations to each other, *regardless* of whether royalty payments, compensation, community development funds, or other forms of “benefit” actually materialize in the future. Urban plant vendors in Mexican cities and rural collectives become part of new ethnobotanical collecting practices and political negotiations that are calibrated to ideas of deserving and undeserving “contributors” to the production of pharmaceutical value; patient groups form in order to make demands not just to be consulted but to negotiate royalty payments; the constitution and relative power of indigenous Aguaruna associations in Peru shift seismically with the speculative promise of “benefits” on the horizon (Greene 2004); hospital and biobank governance structures are being reimagined in the idiom of fiduciary relations; “groups” are being called into being and recognized as such, insofar as they can produce a form of “legitimate political representation.” Together, these developments give us a sense of the kind of “publics” required, requested by a range of efforts to redirect the question of distributing the “benefits of research.”

Received vocabularies on the question of publics might tempt us to assimilate these collectives into the publics of “civil society;” the public of “the state;” the “active citizens” of Giddens’ infernal Third Way, or the self-recognizing and identitarian publics of a new kind of bio-sociality or biological citizenship. I am making a claim against such assimilations, a claim that is grand in its refusals but modest in its assertions, for the kinds of associations that are called into being through benefit-sharing are not easily labeled or recognized in such terms. What they share, perhaps, is their status as speculative answers to the question of benefit-sharing, questions that are highly active in other forms and in other domains as well: how to think about entitlements outside the language of rights, how to think about redistribution not (necessarily) effected by “the state,” how to authorize takings as new forms of ethical appropriation?

In the end, I suppose my own form of collectivization is in motion here, one that sees benefit-sharing as neither a question about “the state”, nor of neglected interests just waiting to be properly recognized, but as an experimental political form in which

representative *and* distributive agencies are being re-conferred, re-articulated, re-imagined. In the proliferation of calls for a new ethic of benefit-sharing, we can see some of the ways in which bioscience research effects and requires certain kinds of publicizations: political legitimacies that are configured –in some ways and not others – in the name of a science that can and must give back.

## REFERENCES, incomplete

- Beauchamp, Dan E. and Bonnie Steinbock, eds. 1999. *New Ethics for the Public's Health*. New York and Oxford: Oxford University Press.
- Brown, Michael. 2003. *Who Owns Native Culture?* Harvard University Press.
- . 1998. Should Traditional Knowledge be Copyrighted? *Current Anthropology*.
- Brush, Stephen B., 1999. "Bioprospecting the Public Domain," *Cultural Anthropology*, 14 (4), pp. 535-555.
- Coombe, Rosemary, 2003. "Fear, Hope, and Longing for the Future of Authorship and a Revitalized Public Domain in Global Regimes of Intellectual Property," *DePaul Law Review*, 52(4), pp. 1171-1192.
- Coombe, Rosemary, 2001. "The Recognition of Indigenous Peoples' and Community Knowledge in International Law," *St. Thomas Law Review*, 14(2), pp. 275-285.
- Greaves, Tom, (ed.), 1994. *Intellectual Property Rights for Indigenous Peoples, A Sourcebook*. Oklahoma City: Society for Applied Anthropology.
- Greely, HT. 1997. "The control of genetic research: involving the 'groups between.'" *33 Houston Law Rev* 1397-430.
- Greene, Shane, 2004. "Indigenous Peoples, Incorporated? Culture as Politics, Culture as Property in Contemporary Bioprospecting Deals," *Current Anthropology* 45(2), 211-237.
- Greene, Shane, 2002. "Intellectual Property, Resources, or Territory? Reframing the Debate over Indigenous rights, Traditional Knowledge, and Pharmaceutical Bioprospection," In: M. P. Bradley and P. Petro (eds.), *Truth Claims: Representation and Human Rights*, New Brunswick, New Jersey and London: Rutgers University Press, pp. 229-249.
- Harrison, Charlotte. 2002. "Neither Moore nor the Market: Alternative Models for Compensation Contributors of Human Tissue." *American Journal of Law and Medicine* 28: 77-105.
- Hayden, Cori, 2003a. "From market to market: bioprospecting's idioms of inclusion," *American Ethnologist*, 30(3), pp. 1-13.
- Hayden, Cori, 2003b. *When Nature Goes Public: The Making and Unmaking of Bioprospecting in Mexico*, Princeton University Press.
- Hubbard, Tim and Jamie Love, 2003. "Medicines Without Barriers," *New Scientist*, 14 June, Comment and Analysis, p.29
- Human Genome Organization (HUGO) Ethics Committee, 2000. Statement on Benefit Sharing. *Clinical Genetics* 58 (5): 364-366.
- Kleinman, Arthur. 1995. "Anthropology of Bioethics" in *Writing at the Margin: Discourse Between Anthropology and Medicine*, 41-67. Berkeley, Los Angeles, and London: University of California Press.

- Knoppers, Bartha. 1999. "Status, sale, and patenting of human genetic material: an international survey". *Nature Genetics* 22: 23-26.
- Knoppers et al. 1996. "Ethical Issues in International Collaborative Research on the Human Genome: the HGP and the HGDP" 34 *Genomics* 272, 275.
- Merz, Jon F., David Magnus, Mildred K. Cho, and Arthur Caplan, 2002. "Protecting Subjects' Interests in Genetics Research," *American Journal of Human Genetics* 70: 965-971.
- North American Regional Committee of the Human Genome Diversity Project, 1997. Model Protocol: Proposed Model Ethical Protocol for Collecting DNA Samples. *Houston Law Review* 33: 1431-1473.
- Parker, Michael, editor, 1999. *Ethics and Community in the Health Care Professions*. London: Routledge.
- Parker, Michael. 1999. Introduction, Health care ethics: liberty, community, or participation?, In M. Parker, ed. *Ethics and Community in the Health Care Professions*, 1-14. London: Routledge.
- Parry, Bronwyn, 2004. *Trading the Genome: Investigating the Commodification of Bio-Information*. New York: Columbia University Press.
- Posey, Darrell A., 1996. "Traditional Resource Rights: International Instruments for Protection and Compensation for Indigenous Peoples and Local Communities," Gland Switzerland, IUCN and the World Conservation Union.
- Povinelli, Elizabeth. 2002. *The Cunning of Recognition: Indigenous Alterities and the Making of Australian Multiculturalism*. Durham: Duke University Press.
- Scott, James. 1976. *The Moral Economy of the Peasant*. New Haven: Yale University Press.
- Sittenfeld, Ana and R. Gámez, 1993. Biodiversity Prospecting by INBio. In: Walter Reid, et al. (eds.) *Biodiversity Prospecting: Using Genetic Resources for Sustainable Development*. Washington, D.C., World Resources Institute; Instituto Nacional de Biodiversidad; Rainforest Alliance; African Centre for Technology Studies. pp. 69-98.
- Urban, Greg and Joel Sherzer, eds. 1991. *Nation-states and Indians in Latin America*. Austin: University of Texas Press.
- Strathern, Marilyn. 2000. 'Accountability...and ethnography,' in *Audit Cultures: Anthropological Studies in Accountability, Ethics, and the Academy*, edited by Marilyn Strathern, 279-304. London: Routledge.
- . 1988. *The Gender of the Gift*. University of California Press.
- Titmuss, Richard. 1973. *The gift relation: from human blood to social policy*.
- Tutton, Richard. 2004. "Person, property, and gift: exploring languages of tissue donation to biomedical research" . In Richard Tutton and Oonagh Corrigan, eds. *Genetic Databases: Socio-ethical issues in the collection and use of DNA*, pp .19-38. London: Routledge.

Weijer, Charles, 2000. "Benefit-sharing and other protections for communities in genetic research," *Clinical Genetics*, 58, pp. 367-368.

Weijer, Charles, Gary Goldsand, and Ezekial J. Emanuel. 1999. Protecting communities in research: current guidelines and limits of extrapolation. *Nature Genetics* 23 (3): 275-280.

Winickoff, D. and Winickoff, R. 2003. "The charitable trust as a model for genomic biobanks." 349 *New England Journal of Medicine*. 1180-4.

Winickoff, D. 2003. "Governing population genomics: law, bioethics, and biopolitics in three case studies." 43 *Jurimetrics*. 187-228.

Wolf, Susan F., ed. 1996. *Feminism and Bioethics: Beyond Reproduction*. New York and Oxford: Oxford University Press.