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ABSTRACT A growing number of bioethicists, policy-makers, legal scholars, patient groups, and other critically involved parties in North America and Europe recently have started calling for a new ethical principle to gather participants into clinical and genetics research. While long-prevailing regimes of consent have held that people participate in the research process out of 'altruism' (and hence do not merit more than nominal payment for their participation), the increasingly visible profits accruing to bioscience researchers, companies, and universities suggest that this research contract is producing a stark asymmetry. A move is afoot, therefore, to develop a principle of *benefit-sharing* through which to guarantee some form of returns to research subjects. This paper tracks some of the implications of the rise of this new ethic, tracing its travels from the world of bioprospecting to clinical and genetics research, and exploring how and why benefit-sharing matters to Latourian notions of science as politics. 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', in Latourian terms, but as a mode of giving back? I argue that in shifting the problem from one of dialogue to one of distribution, benefit-sharing proposals are also implicated in the constitution of the biosciences' publics in new ways.

Keywords bioethics, bioprospecting, Europe, genetics, indigenous peoples, intellectual property, North America, publics

Taking as Giving:

Bioscience, Exchange, and the Politics of Benefit-sharing

Cori Hayden

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. (Merz et al., 2002: 965)

This marvelously assertive quote from a biomedical consent form is Exhibit A in a recent paper by US 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 USA and

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Europe insist that people participate in the research process out of ‘altruism’ and that tissue, blood, or gene samples donated or removed during treatment are a gift with no strings attached. Yet it becomes ever more obvious, even in the way that consent is requested, that such gifts may well enable quite a lot of profit for those on the receiving end of these transactions. The rise of commercialization in the biomedical sciences has become apparent on many fronts. Most broadly, of course, the liberal interpretations of novelty and innovation that have prevailed in the US Patent and Trademark Office since 1980 have made the patenting of genes and gene sequences (by companies and researchers) close to routine. The explosion of private tissue and biobanks in the USA, Europe, and beyond, has created vast storehouses of biological matter (and bio-information) with great potential for generating commercial value (Tutton & Corrigan, 2004; Parry, 2005; Waldby & Mitchell, 2005). Diagnostic tests developed out of gene and tissue samples (such as the BRCA breast cancer screening protocols monopolized in the USA by Myriad Genetics) have become major sources of revenue for genetics and biotechnology companies (Parthasarathy, 2005).

As biological samples and their derivatives become increasingly visible as lucrative forms of property for companies, many have raised questions about the rights of those who provide this bio-matter in the first place. The highly vexed and vexing question of whether or not the playing field should be leveled by giving patients property rights to their own organs and tissue has come up in many a forum (Boyle, 1996; Cohen, 1999; Waldby & Mitchell, 2005). Perhaps the best-known touchstone on this point within the USA is the 1990 case, *Moore v. Regents of California*, in which the California Supreme Court ruled that John Moore, a patient at the University of California, Los Angeles (UCLA) hospital, had every right to *know* that his doctors might make a profit out of his spleen cells (*Moore v. Regents of the University of California*, 793 P.2d 479 [Cal. 1990]). But the Court denied his claim that medical researchers had unlawfully ‘converted’ his own property (his cells) into their property (a patent), and thus argued that Moore did *not* have a right to a share of the proceeds (Boyle, 1996; Jasanoff, 2005: 213–15). This decision famously drew on and thus reaffirmed the long-prevailing biomedical consensus that research is, fundamentally, for the ‘good of humanity’ and that participation must continue to be rendered as an act of gift-giving or donation, with no basis for a direct claim for ‘getting back’.

It is precisely this shaky and unsatisfying post-Moore consensus – informed consent, yes, direct benefits, no – that Merz and colleagues, alongside many other critics, 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 prototypical 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. From novel calls to import ‘open source’ software models into the biosciences to bioprospecting agreements for drug discovery

that now include promises to return benefits to developing nations and local communities (about which more below), the relationship between giving and getting is being fundamentally re-thought on many fronts.

A growing number of bioethicists, policy-makers, legal scholars, patient groups, and other critically involved parties have recently, and vociferously, started calling for a new ethical principle to supplant the long-reigning notion of altruism, and to supplement the key tool in the bioethical toolbox, informed consent. This novel principle is *benefit-sharing*, and 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. These proposals take a range of forms and emerge out of a number of different kinds of concerns. For the Human Genome Organization (HUGO) Ethics Committee, benefit-sharing is a principle that emerges quite naturally out of HUGO's signature commitment to treating the information generated by the Human Genome Project as the 'common heritage of humanity', and thus as something that must not be cordoned off in overly restrictive proprietary arrangements (Human Genome Organization Ethics Committee, 2000). For some patient activist groups and their bioethical advocates in the USA, benefit-sharing refers to a new ethical stance in which those who participate in (and often fund or otherwise enable) research are entitled to benefit from the outcomes of research; this is the kind of project towards which the University of Pennsylvania's bioethics initiative, 'Toward an Understanding of Benefit-Sharing' is directed (Center for Bioethics, 2001).¹ In yet another iteration, debates over the governance of biobanks and tissue collections in nations such as Iceland, Estonia, Sweden, the USA, the UK, and India have brought to the fore a range of demands that these public-private exercises in tissue and information collection include sufficient guarantees to 'give back' to the appropriate constituency, which is often seen as 'the nation' itself (see Hoyer, 2004; Tutton & Corrigan, 2004; Pálsson & Rabinow, 2005; Sunder Rajan, 2006). The term 'benefit-sharing' also turns up quite frequently as a new if arguably vague guarantor of accountability, as in recent deliberations by expert bodies such as UNESCO's International Committee on Biotechnology and the US President's Task Force on Organ Donation.

My task in this paper is neither to join nor to oppose this heterogeneous chorus of calls for new ways of imagining the research contract, but rather to step back and track some of the implications of the growing tide of calls for benefit-sharing, both in the realm of clinical research and in the context of bioprospecting. While many of these calls circulate in the language of 'ethics', my aim in this essay is in part to re-frame benefit-sharing as a kind of politics, or at least as an exercise in political imagination. In science studies and allied fields, much attention has been paid to the ways in which bioscience research is implicated in modes of governance, deliberation, and processes of representation (Jasanoff, 2004, 2005; Latour, 2004). Equally relevant to the topic at hand, scholars of intellectual property such as Rosemary Coombe point to how creative and even oppositional uses

of intellectual property can help foment new kinds of ‘dialogic democracy’ (Coombe, 1998, 2003). These points move us firmly into an argument about the mutual constitution or ‘co-production’ of bioscience and politics (Jasanoff, 2004), where politics figures in a somewhat Habermasian idiom of dialogue, decision-making, and debate. Benefit-sharing proposals draw our attention to some important and underexamined questions on this front. By shifting the emphasis from *dialogue* to exchange or *distribution*, benefit-sharing proposals, I will argue in this essay, are constituting ‘publics’ or collectives in ways that demand a revised engagement from a science studies-inflected point of view.

Authorizing Bioscience: From ‘Speaking For’ to ‘Giving Back’

Social and anthropological studies of science have provided us with a rich legacy of critical inquiry on how publics, and political and social orders, come into being as an integral aspect of the legitimation of scientific knowledge (Latour, 1993, 2005; Haraway, 1997; Jasanoff, 2004). From the much-mutated notion of the ‘modest witness’² to Latour and Callon’s versions of Actor Network Theory (Callon, 1986; Latour, 1993), the figure of the credible spokesperson and the act of ‘speaking-for’ have been key mediators in the operation through which science studies scholars have argued that science is politics by other means. Bruno Latour in particular has emphasized these idioms of speech and speaking-for in his rather distinctive notion of science as itself a ‘parliament’ or a process of forging a new ‘democratic collective’. For Latour, scientific knowledge performs a kind of double representational act, bringing the realms of nature and politics together in one fell swoop. That is, authoritative science both represents or ‘depicts’ nature and represents, or speaks for, the dense webs of interests of those people and things that have been gathered-to, enrolled, or ‘interested’ in the fact in question (Latour, 1993: 27). Much of Latour’s work has been dedicated to showing how, in such gatherings-to and acts of ‘speaking for’, new publics and new collectives also, necessarily, take shape (see Latour, 2004, 2005).

For a suggestive extension of this kind of argument from the contemporary biosciences themselves, we might look to the remarkable carnival of ‘public participation’ that has surrounded policy-makers’ efforts in the UK to grapple with and legitimate controversial arenas of research, from in vitro fertilization in the late 1980s, to cloning, stem cell research, and genetically modified crops in the present. Repeatedly calling into being a public that may then be consulted, researchers and policy-makers have made recourse to a wide range of mechanisms, from parliamentary commissions, to focus groups and public forums such as the 2003 ‘GM Nation?’ debates, in order to take the public – or society – into account (Strathern, 2002; Franklin, 2003; Irwin, 2003; Jasanoff, 2005). The goal, in many instances, has been nothing less than the development of what European science studies scholars are calling ‘socially robust’ scientific research

(Nowotny et al., 2001). Significantly, legal scholar Katherine Liddell (2003) refers to 'biolaw' in this arena precisely as an exercise in deliberative democracy. Indeed, these processes offer a powerful confirmation of the notion of science as a process of speaking for, of designating spokespersons, and of representing interests.

But it is not just the public forum that serves as a legitimating and publics-making device where controversial biomedical or bioscientific research are concerned. As many scholars of the biosciences have noted, bioethics – the practice, the discourse, and the institutional arena – has become one of the more influential sites for gathering people into and thus brokering the legitimacy of bioscience research over the last 40 years, especially in the USA and the UK (Franklin, 2003; Jasanoff, 2005). To use a Foucaultian phrase via Nikolas Rose, bioethics has become central to the ways in which bioscience's authority is itself 'authorized' or legitimated (see Rose, 1999: 167–96; see also Rabinow, 1992). This is precisely the case in modes of research that explicitly require human participation, such as pharmaceutical trials, biobank collections, and other kinds of clinical research. Here, to borrow a turn of phrase from Marilyn Strathern (2000: 292–94), there is a world of difference between 'including people' and 'including them *well*' (that is, ensuring that their participation does not become a form of exploitation or mistreatment).

My contention in this paper is that, with shifts in understandings of the nature of the contemporary research enterprise, we also see shifts in understandings of what it means *to include people well*. What are the implications of a new emphasis in idioms of gathering-to, which brings distribution and exchange to the fore? The rise of benefit-sharing matters for notions of science as politics precisely because of the ways in which its proponents are articulating a different kind of representational project. 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 animates, simultaneously, exercises in public participation, a Latourian notion of politics and even revised theories of informed consent. In all of these arenas, inclusion tends to mean dialogue, the incorporation of different points of view, or the transparent disclosure of information. Something arguably different is afoot when benefit-sharing is on the table: inclusion is figured explicitly as participation in processes of value production. What might it mean then, 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?

The discussion that follows proceeds in three major sections. The first discusses the emergence of benefit-sharing in the context of bioprospecting, where it originated in the late 1980s and early 1990s. The second addresses the contours and requirements of benefit-sharing as it becomes

incorporated into discussions of clinical and genetics research. The final section brings us back to the matter of re-framing benefit-sharing from an ethical to a political matter, elucidating both how and why these proposals for re-imagining what will count as an ethical mode of inclusion produce new kinds of publics or collectives.

The Travels of Benefit-Sharing: From Bioprospecting to Clinical Research

While the notion of the ‘benefits of research’ has a long history in discussions of the relationship between public good and private reward in the biomedical sciences, ‘benefit-sharing’ as a specific principle of research governance has a recent and rather concretely identifiable history. The language of benefit-sharing emerged in part out of ‘Common Heritage’ initiatives in international law, which sought to address the question of how to distribute rights to exploit and benefit from natural resources (see Sheremeta & Knoppers, 2003: 95). The term had its most high-profile debut in the 1992 UN Convention on Biological Diversity (CBD), a multilateral instrument which aimed to re-frame the international traffic, management, and commercial exploitation of biodiversity (such as plants, microbes, and insects) and traditional knowledge. It was in this context that I first became interested in how an extractive and hybrid scientific/corporate endeavor, such as collecting plants and traditional knowledge as leads for new drugs, has become reconfigured as a potentially ‘ethical’ act in which biotechnology- or pharmaceutical-derived royalties would come back to source communities and nations in the form of compensation, funds for economic development, and technology transfer (see Hayden 2003b).

Beginning in roughly 1996, bioethicists and policy-makers working on guidelines for clinical research, genetic databases, and blood, tissue, and cell banks became avid champions of the quasi-redistributive impulse of benefit-sharing as well. There are certainly many things that differentiate these two domains of benefit-sharing discourse and practice. Indeed, in early statements on the importance of developing a new ethic of benefit-sharing in (human) genetics research, Bartha Maria Knoppers, a Montreal-based legal scholar and then-Chair of the HUGO Ethics Committee, declared as a matter of course that one realm (that of the CBD, indigenous rights, and natural resources) had virtually nothing to do with the other (clinical research and bioethics protocols) (cited in Parry, 2005: 74). The two arenas, Knoppers suggested, concern radically different kinds of bio-material, research infrastructures, and governance.

But there are, arguably, many reasons to think about these two arenas of benefit-sharing together. Some of these reasons hover in the realm of policy applications, as my colleague, the geographer Bronwyn Parry, has argued forcefully in her account of how lessons learned from bioprospecting agreements should be carefully studied by ethicists seeking to implement benefit-sharing in the clinical realm (Parry, 2005). I am interested in a somewhat different register of traffic back and forth between these

domains. With my eye on the questions of how and why benefit-sharing requires its publics to take a particular form, I begin with a brief discussion of bioprospecting as one site for understanding the ‘collectivizing’ operations that research organizations, scientists, and funding bodies argue are necessary, if bioscience research is to become a more deliberately reciprocal form of exchange.

Bioprospecting: Community as a Site of Conversion

Bioprospecting is an explicitly extractive mode of research in which unequal relations of exchange have been the salient issue, in varying ways, for indigenous organizations, Southern environmental and social justice activists, and proponents of sustainable development and conservation since the late 1980s. The 1992 UN Convention on Biological Diversity was (and remains) the touchstone document in efforts to address the inequities that seemed so starkly on display when (to invoke an oft-cited example of ‘biopiracy’ from the 1960s) a transnational drug company patented a highly profitable leukemia drug, vincristine, which was derived from the rosy periwinkle plant collected in Madagascar, but was under no obligation to share proceeds with the nation or communities of people who led researchers to this plant in the first place. The CBD’s benefit-sharing provisions 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 CBD (which the USA has not ratified), these resources can now be subject to new kinds of claim-making by nations and communities of the global South. The CBD’s benefit-sharing mandate is itself a reflection of conflicting interests, as it has been understood by Northern conservationists as an incentive for poorer nations and communities to manage their biodiversity, and by many Southern and indigenous activists as a matter of social justice.

As a matter of governance, 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, and in a spate of private and public benefit-sharing contracts themselves which have played out to often contradictory effect (Hayden, 2003a,b; Greene, 2004). The benefit-sharing principle in particular has also been elaborated upon in a series of follow-up conventions, most prominently that which produced the 2002 Bonn Guidelines on ‘Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilization’.³ The Bonn Guidelines make explicit, for example, that the CBD does not apply to human genetic resources (the CBD was not explicit on this point), and they emphasize the importance of prior informed consent for working with community resources. They also lay 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). As will become apparent below, this menu of potential benefits has made its way into proposals for benefit-sharing in the context of clinical and genetics research as well.

As we might surmise, a host of simultaneously technical and highly charged political questions face those calling for, designing, and participating in benefit-sharing agreements. Among these questions are: What precisely shall count as an appropriate form of return (technology transfer, royalty payments, infrastructure building, community development projects)?; How much would be considered 'equitable' (royalty payments often hover in the range of one to three percent)?; and who shall be considered a benefit recipient (national biodiversity institutes, some communities and not others, developing country scientists)? I have written extensively about the fate of the latter question in a USA–Latin America prospecting agreement that lasted from 1993 to 2000, in which researchers in Mexico, Chile, and Argentina were under contract to send plant material or plant extracts to their US academic host, the University of Arizona, and to the US-based life sciences firm American Cyanamid (Hayden, 2003b). 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 one-half of that amount would then be transferred to the appropriate source country, to be distributed among the relevant institutions and participating communities (Hayden, 2003b: 71–73). This project was one of a number of publicly funded prospecting collaborations supported by the US National Institutes of Health (NIH) under the auspices of a sustainable development and drug discovery initiative called the International Cooperative Biodiversity Groups (ICBG) program.⁴ Its machinations, particularly in Mexico where I conducted the bulk of my ethnographic research, highlight a number of crucial issues for understanding the extension of benefit-sharing to new domains.

Intriguingly foreshadowing some of the issues that seem to be reshaping clinical and genetic research, the Mexican ethnobotanists with whom I worked told me that things had changed in important ways in the post-CBD environment: 'you don't just collect plants anymore'; you must also collect, or gather into the research process, the people whose interests and potential claims come with those plants (Hayden 2003b: 232). Long before any 'benefits' even have a chance to trickle back, these scientists and their local interlocutors must start to sort out the key questions for the new ethic of benefit-sharing: on what basis shall people and their claims be attached to the inputs and outputs of research? In the agreement I studied, the NIH 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 this equation 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.

As we shall see in subsequent sections, the notion of who or what shall define 'community' has been a key question in research involving indigenous populations, whether in the field of population genetics (see Reardon, 2005), or, as in this case, natural products drug discovery. Here, I want to highlight the somewhat odd way in which the NIH's appeal to 'community' as a collecting site came to hold a certain importance. For a variety of complex reasons which I have addressed at length elsewhere, the participating Mexican ethnobotanists initially re-engineered the NIH's model of linking plants-collected to benefits-promised, opting at first to steer clear of 'communities' and to collect plants in urban markets (Hayden, 2003a). That is, they bought plants from urban vendors, turning this round of resource appropriation into an explicit commodity exchange. Vendors were paid their asking price for 1 kg of dried *matarique*, for example, but were not considered future benefit-recipients because they were not seen as original 'sources' of knowledge or information and thus were not asked to sign benefit-sharing contracts (see Hayden, 2003a).⁵ The researchers instead negotiated benefit-sharing relations *parallel* to the process of collecting resources, enrolling organizations such as a group of traditional healers who wanted to start an ethnobotanical garden in Oaxaca, and a collective organic bean cultivation project in the Sierra Tarahumara in Chihuahua to be future benefit-recipients, should royalties emerge from the drug discovery pipeline.

Program administrators at the NIH found this detour around the notion of community unsettling, precisely because the plants collected this way do not come with contract-signing benefit-sharing recipients attached. Plant collecting 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 plan by a team of US ethnobotanists 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 the question of who had the right to broker access to these 'ethical appropriations'.⁶ The NIH ended up canceling the Chiapas project altogether in 2000 (see Brown, 2003).

Smarting slightly from the controversy, the ICBG project director insisted to the director of the first Mexican ethnobotanical team that he *cease* his market work altogether and work *exclusively* with 'contract-signing communities'. This response might not make much sense without an understanding that community – imagined 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.

What might we take from this episode? 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 (Joseph, 2002), but also, simultaneously, as the form of political sociality that 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 such as Mexico. But I 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.

Benefit-Sharing: Clinical and Genetic Research

It is not just medicinal plants and traditional knowledge that serve as potential sources of value and around which new modes of ‘participation’ and claims-making have emerged. Just as the CBD declared that biodiversity and cultural knowledge should no longer be considered free for the taking, ethical and legal conventions naming biomedical research subjects as altruistic gift-givers have also come under significant fire. In light of the fortunes that may be derived from ‘human biologicals’, the idea of implementing a more direct, traceable (re)distribution of the fruits of research has been gaining ground in this arena as well.

Benefit-sharing in clinical research has emerged in the context of a twofold set of shifts: a widespread critique of the asymmetrical effects of commercialization, and the strong emergence in bioethical circuits of the notion of a collective research subject. Each of these has been amply documented by commentators and participants in the field; my interest, however, is in the consequential and even, perhaps, necessary relationship between the two. Examining this relationship helps us track how and why critiques of commercialization are helping to generate a proliferation of new collective entities.

In the 1990s, patient groups in the USA, among other actors, actively began to reformulate current economies of participation and profit in clinical research. Genetics research in particular has spawned groups and foundations that are playing a remarkably active role in facilitating research, with patient or family groups themselves often funding studies, recruiting participants, creating DNA banks, and enrolling tissue and blood donors (see Rabeharisoa & Callon, 1998). It is precisely such processes – and the forms of subjectivity, collective identification, and new modes of activism that are crucial thereto – that have inspired recent arguments that we are witnessing the genesis of new modes of biosociality (Rabinow, 1992) or ‘biological’ or ‘genetic’ citizenship (Rapp et al., 2004; Rose & Novas, 2004; see also Petryna, 2002).

Among the best-known examples of such patient activism in the USA have been the family-led mobilizations around such conditions as Canavan disease and the connective tissue disorder pseudoxanthoma elasticum (PXE). For some

commentators, these examples are serving not just as models of a new form of biological citizenship, but for a new research model based on benefit-sharing. Canavan disease is a single-gene, degenerative neurological disorder that appears at birth; children with the condition are likely to die before their teens. Research on this relatively rare condition was sparked by the efforts of one couple in particular, Dan and Debbie Greenberg, whose two children were born with the disease in the early 1980s. Following this double diagnosis, Dan Greenberg approached a researcher working on related diseases; the Greenbergs and another family provided tissue, blood, and urine samples for the research effort; and Dan Greenberg's Chicago Chapter of the National Tay-Sachs and Allied Diseases Association allocated seed money for research on the disease. The results of these initiatives were quick and tangible: within a year, the researcher, Reuben Matalon, identified an enzyme deficiency as the cause of the disease, and a prenatal diagnostic test was developed on the basis of this discovery. But the story quickly became thorny, as the research foundation that developed the diagnostic test, Miami Children's Hospital, aggressively defended its patent and would not allow others, including community foundations and organizations that helped organize subsequent tissue collections, to use the screening test. Greenberg and an allied organization sued Miami Children's Hospital in 2000, seeking to liberate the diagnostic test from restrictive, proprietary control (Canavan Foundation 2003; Marshall 2000; Merz, Magnus, Cho and Kaplan 2002: 966; see also Rapp, Health, and Taussig 2004). As a rather stark example of a radical disconnect between research participants' enabling participation and corporate monopoly rights over the research results, the struggles over Canavan disease became, we might venture, an analog to the rosy periwinkle tale in the annals of biopiracy. The PXE tale, in contrast, holds a rather different place for those looking for examples of benefit-sharing models: the dominant advocacy organization in this realm, PXE International, has both helped support research on the disease, and has managed to retain rights in resulting patents (see Rose & Novas, 2004: 456).

Undoing 'Undue Inducement'?

Families affected by genetic conditions such as Canavan disease and PXE have thus been making concrete demands on the end-results of research in which they are leading participants. 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 are actions that seem reasonable, fair, and certainly even ethical. But they are also potentially troubling to the very bioethical principles and 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 direct returns on their involvement. For

example, it is standard practice though not starkly codified in the USA 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 render the trial illegitimate. International conventions have been more explicit. The HUGO Ethics Committee wrote in 1996 that ‘[u]ndue inducement through compensation for individual participants, families, and populations should be prohibited’ (quoted 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’ (quoted 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. We might think here of drug trials on prisoners in the USA, or the fact that participation in clinical trials is often the only way to gain access to experimental or otherwise unavailable treatment. Breast cancer and HIV/AIDS activists in the USA made the latter 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 (see Petryna, 2005). Clinical research is always, arguably, an exchange, and often an asymmetrical one, 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 the USA and European biomedical circuits as a *gift to strangers*.⁷ But this mode of including people fairly, or of precluding exploitation of research subjects, is now increasingly seen as a potential source of injustice (see Tutton, 2004). 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 a diffuse 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. How or on what grounds are these discussions attempting to recast the prohibition against undue inducement?

Some ethicists have looked ‘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). This rosy assessment of universal feelings on the matter of North–South relations certainly gives pause, but there

is something more important on display here. Such a proposition alerts us to a crucial aspect of the rise of benefit-sharing, which we might call the ‘third worldification’ of the first-world research subject. Benefit-sharing in the domain of bioprospecting started from the proposition that bioscience is a kind of asymmetrical resource extraction that might now be made ‘ethical’ or equitable. Here, previously ‘ethical’ research is now being recoded as a form of asymmetrical resource extraction.

In fact, prominent international entities such as HUGO invoke the notions of fairness, justice, and the international law concept of ‘common heritage’ to carve out a space for an ethical reciprocity that is, potentially, different from both unfettered appropriation and unethical inducement. In 2000, the HUGO Ethics Committee drafted its widely circulated ‘Statement on Benefit-Sharing’, which set out a number of principles meant to elicit discussion and further elaboration of this new ethic. The Statement’s six recommendations, which take us in a rather breathtaking arc from protecting ‘humanity’ to the importance of the thank-you letter, read as follows:

- (1) that all humanity share in, and have access to, the benefits of genetic research;
- (2) that benefits not be limited to those individuals who participated in such research;
- (3) that there be prior discussion with groups or communities on the issue of benefit-sharing;
- (4) that even in the absence of profits, immediate health benefits as determined by community needs could be provided;
- (5) that at a minimum, all research participants should receive information about general research outcomes and an indication of appreciation;
- (6) that profit-making entities dedicate a percentage (e.g. 1–3%) of their annual net profit to healthcare infrastructure and/or to humanitarian efforts. (Human Genome Organization Ethics Committee 2000: 366)

What is the relationship between these recommendations and HUGO’s own statement of 1996, cited previously, that explicitly prohibits undue inducement in the form of ‘compensation to individual participants, families, and populations’? The earlier prohibition itself, it turns out, contained a significant caveat. The 1996 HUGO statement continued its remarks on undue inducement as follows: ‘This prohibition does not include agreements with individuals, families, groups, communities or populations that foresee technology transfer, local training, joint ventures, provision of healthcare or of information, infrastructures, reimbursement of costs, or the possible use of a percentage of any royalties for humanitarian purposes’ (cited in the Human Genome Organization Ethics Committee, 2000: 364). The difference between unethical inducement and ethical benefit-sharing rests, as we will see, on what is given back and on who is on the receiving end of the returns.

The 'Problem' with Altruism

The most direct critique of the long-prevailing order – and thus the most specific articulation of what must be done instead, and why – has come from the researchers whose arguments provided the opening to this essay. Jon Merz and colleagues, working as part of the University of Pennsylvania's project on benefit-sharing, have worked extensively with Canavan's disease and PXE family groups, and they are taking seriously the challenge to elaborate a philosophy on which a new research relationship might be forged. In the 2002 paper 'Protecting Subjects' Interests in Genetics Research' cited earlier, Merz and colleagues make their case against the existing definition of ethical modes of inclusion:

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. (Merz et al., 2002: 969)

With this strong statement, we confront, again, the key logistical–theoretical question that haunts and defines any benefit-sharing proposal: In what idiom shall people and their claims be attached to the inputs and outputs of research? If HUGO gains its moral authority from appeals to common heritage, these researchers and advocates clearly take a different tack, with an appeal to the markedly neoliberal language of stakeholder theory and 'interests in need of recognition'. 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 (in Recommendation 6) is arbitrary and 'does not reflect any economic analysis of relative contribution or fairness' (Merz et al., 2002: 969). They give hedging support to the idea of royalty-distribution – as long as it does not inflate prices downstream (pp. 968–69). They also 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 also it may turn out to be worth nothing at all (p. 969). The possibility that it might be worthless presumably saves ethicists and corporations from the specter of undue inducement.

But in this thicket of potential remedies, Merz et al. also are tremendously clear about how *not* to recognize and reward participant interests. After establishing unequivocally 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 et al., 2002: 970, emphasis added).

Not-property

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 this particular articulation. Many 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 and definitively 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 (Greene, 2004). 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 to find recourse to a wide range of other idioms of return such as donation, incentive, up-front payments or access fees, or technology transfer – none of which require, assume, or produce rights claims (see Greene, 2002; Hayden, 2003a).

So, too, in the realm of clinical research. Careful to reaffirm the right of firms to accumulate intellectual property claims on biologicals and their derivatives, the University of Pennsylvania discussion and many others like it desperately want to avoid what seems to be their Hayekian nightmare (a pure bargaining democracy), and the solution towards which John Moore himself was heading: property rights for each of us in our own DNA and organs; an open market in kidneys and spleen tissue; the prospect of indigenous patents or copyright (see Brown, 1998); even, we might recall, plant collection 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 Pennsylvania team's articulation thereof, the NIH's prospecting program, the HUGO Ethics Committee's Statement on Benefit Sharing, and many others as well (M. Stears, personal communication, 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 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; that is, in how and why bioethicists' and policy-makers' aversion to investing research participants with rights requires, or at least strongly requests, the production of new collectives.

What is the Collective, and What is it For?

Collectivization is a term I use, advisedly, to signal an important companion to the critique of commercialization that drives benefit-sharing proposals. For it is not just the old staple of altruism that seems to be taking a slightly incoherent hit at the hands of the market and its failures. Out with this principle goes its principal 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 of increasingly well-established critiques of the autonomous individual as the only thinkable, actionable subject of bioethics.⁸ Many such critiques from within the field of ethics itself have focused on processes of decision-making, drawing on communitarian political theory and an explicitly Habermasian notion of communicative rationality as they call for a more relational and dialogical notion of the ethical subject (Kleinman, 1995; Wolf, 1996; Parker, 1999; Callahan, 2003).

Genetic research in particular has given a sense of urgency to such efforts to place collective subjects at the heart of the consent process. 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’, and even entire nations (such as Iceland, Estonia, and 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 would not cede the definition of genetically defined groups as so blindingly obvious, but that is a point for another forum.⁹

Bartha Maria Knoppers, chair of the 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 US 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 fourth and first 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, 2005; see also Knoppers et al 1996). As Greely and a number of his colleagues on the North American Regional Committee of the HGDP noted, a new 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).

But of course, as Jennifer Reardon has shown so clearly in her work on the HGDP, one of the operations necessary to the project's embattled efforts to pioneer a new form of consent is precisely the 'assumption that groups exist' (Reardon, 2005: 99–100). Such an assumption often leads to the creation of contract-signing collective entities in the first place (*ibid.*). In other words, and in a process equally visible in the annals of bio-prospecting, 'groups' are not necessarily the precondition but rather the result of efforts to obtain collective consent.

If the HGDP's notion of group consent was an adaptation of western informed consent models to indigenous or aboriginal communities (Reardon, 2005: 124), benefit-sharing discussions show us how such borrowings continue to ricochet, and how these forms of collectivization take on a particular burden when the problem of redistributing 'value' is on the table. We might recall Kare Berg's proposition, cited earlier, that the unremunerated exploitation of developing nations' resources could serve as an analog to the unfair appropriation of family groups' DNA by pharmaceutical companies. In fact, the specter of indigeneity and of North–South inequities serves as a resource in these discussions in multiple ways.

For example, with the HGDP's models of community consent well institutionalized in a number of research contexts, 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, 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 now 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, Nova Scotia (Canada)-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 rather uncritically from the skeleton-laden anthropological closet, Weijer, Goldsand, and Emanuel (1999: 279) wrote, '[a]boriginal communities tend to be geographically localized, bound by shared histories, cultural traditions, languages ... But other communities lack these morally

relevant features ...'. 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' (ibid; see also Weijer 2000).

Echoing and arguably granting new life to processes readily visible in the histories of colonialism and development, the vexed question of what community *is* thus dissolves into the much more streamlined question of what community *does*. To recall the query with which I opened this essay, we might suggest that a Latourian 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 genetic disease activist groups in the USA:

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)

With this position, Merz and colleagues join the HUGO Ethics Committee in arguing that it is communities or groups (even populations and nations) *rather than individuals* that serve as the viable subjects of benefit-sharing. And their position, crucially, is based not just on an assumption that groups exist; it is also an incitement to form groups with the purpose of negotiating patients' proper place – as sources of valued material and as 'stakeholders' — in the process of biomedical value production.

This observation leads me to a concluding argument for this section, and a main argument of the essay overall. It is not just the empirical 'fact' that genetic and other kinds of research involves groups which is prompting ever-expanding efforts to name and enable collective ethical subjects. Such processes of collectivization are also a corollary of the increasingly respectable, mainstream ethical understanding that biomedical research is explicitly a process of resource extraction and value production.¹⁰ Benefit-sharing steps in as a way to *facilitate* and legitimate this process by turning takings into promises of giving back. And, if including people well means returning benefits, then, of course, these returns require a destination. In the matter of giving back in clinical or genetics research, the individual is a nervous-making entity: a conduit to the specters of property rights, commodity exchange, and 'undue inducement'. Its disavowal takes us *necessarily* to the – a – collective. Thus, I would argue, 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'.

I opened this essay by asking about the kinds of political sociality that are 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, something else has become less clear. What does this answer tell us about the kind of entitlement that benefit-sharing is meant to be?

Debates over participation in the increasingly commodified world of bioscience research frequently hover in the durable problem-space of 'gift' versus 'commodity', drawn, sometimes badly, from Marcel Mauss' work in the early 20th century (see Tutton [2004] for an excellent discussion).¹¹ The intriguing problem with the question of benefit-sharing is precisely that we are not in the 'old' terrain of gift versus commodity, 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, Henry Greely 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 (that is, the state), tended to be unassimilable to conventional US bioethical protocols (Greely, 1997).

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 policy-makers advancing proposals for benefit-sharing, community-as-group *grounds* a kind of exchange that 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, even nervously, in the space between (not-) rights and 'what is right'.

From the Ethics of Benefit-Sharing to the Politics of Distribution

Postcolonial theorist Achille Mbembe and Mexican sociologist Julio Boltvinik (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, 2001: 84). Mbembe was writing of postcolonial Francophone Africa, and Boltvinik, of political trends in contemporary Mexico, which, he argues, have made the proper person a receiver of transfers rather than a subject of rights (Boltvinik & Hernández Laos 2000: 14).¹² Transfers, allocations, and distributions are terms that take us out of the artificially isolated spheres of market and exchange, and gift and commodity. They remind us that the sharing of benefits is also an idiom of politics, social contracts, and conflicting traditions of thinking about the state, too, as that which performs and regulates acts of taking and giving back.

In this final section, which serves as an extended coda to the arguments offered above, I propose that we think about the rise of benefit-sharing and

the supposed death of altruism as another kind of story, one that is not exclusively about unequal relations of exchange but one that concerns broader infrastructures of distribution and redistribution. The designated high priest of post-war British social policy, Richard Titmuss, certainly would have posed the problem in these terms, and in fact we might argue that he already did so, in his 1973 study of the British voluntary blood donation system, *The Gift Relationship: From Human Blood to Social Policy*. 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 US-based ethicists on whose work I've been drawing to talk about benefit-sharing, Titmuss placed the state at the center of his effort to answer this question. 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 *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 healthcare. As Marc Stears has noted, in Titmuss' view, altruism could be the glue that held this society – and one, very influential, post-war biomedical research story – together precisely because a notion of the collective, or public, held a certain value (M. Stears, personal communication, 2004). Not surprisingly, the USA and its highly privatized healthcare infrastructure was the explicit Other in Titmuss' story. He wrote his passionate defense of a social state that must protect the 'right to give' precisely at a moment when the UK was contemplating the Americanization of its blood donation system: that is, 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 USA.¹³ These suggestive contrasts between the USA and the UK do more than serve as place-holders for an argument that things were different then, and/or that things are different there (Tutton, 2004). More to the point, invoking Titmuss reminds us that there are multiple ways of telling the contemporary benefit-sharing story, 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 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 stakeholder interests, badly or better recognized.

Cutting Collectives (I)

What would happen, then, if we followed Titmuss' lead and made genetic benefit-sharing in the realm of clinical research, at least, a question about healthcare systems and the duties and rights of *the* collective? Legal scholar Charlotte Harrison, writing of the USA, where the social state in the British

sense has not been much in evidence for the last 50 years, does just that when she points out that the visions of benefit-sharing that we see most clearly in the USA seem simply to reward those relatively few groups who are best able to make demands. In a 2002 paper in the *American Journal of Law and Medicine*, Harrison looks warily at the growing trend in the USA 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 healthcare 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 vision of patients as stakeholding contributors to processes of value production, I would answer yes, without doubt. These 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. We might do well to focus our attention instead on the decimation of the political and social infrastructures that allow 'altruism' to ground an adequate account of how to include people well in biomedical research. When that way of addressing the 'for whom?' question seems to lay bare an injustice, we start hearing calls for the benefits of research to be recalibrated – 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 explicitly (and many argue, romantically) underwrote the notion of the collective that, in Titmuss' view, enables the 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 selectively from Latour and other conversations in social theory about the idioms through which we might imagine the social, the public, and sociality. While I am not working towards a Latourian 'parliament of things' here, what is of use to me are the theoretical legacies from which he draws in his recent work, and the idiom of *collecting* to which they lead. In *Reassembling the Social*, Latour eschews Durkheim's notion of the social for the more open-ended notion of a sociology of 'association' drawn from Gabriel Tarde as well as the

pragmatist John Dewey. He thus defines his collective as follows: ‘In spite of its use in the singular, the term refers not to an already-established unit but to a *procedure for collecting associations ...*’ (Latour, 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’ (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 a pre-existing whole, but literally making or constituting collective entities; that is, drawing people into association by gathering them (*well*, adequately, or ethically) into the research process. Again, the functions of such entities are not simply representative in the sense of identifying spokespersons; they are also distributive.

In fact, there are a number of thoughtful proposals circulating in the worlds of law and ethics in the USA that, like the proposals we saw above, tackle the problem of giving back by proposing novel forms of collective and distributive agency. But they do so in a way that is quite critical of the privatizing, stakeholding model discussed above. For example, 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. Unlike property rights, which declare that donors have a particular interest in their tissue no matter what the outcome of their act of donation, liability rules are used to determine and apportion compensation in the aftermath of a particular event or grievance, and are based on the idea of damage done, rather than property rights held. Liability rules are used to mediate such things as worker’s compensation claims; here, Harrison argues that they might usefully be applied to determine compensation in the event that particular samples of donated tissue lead to a profitable product (this, she notes, raises still further questions about the traceability of samples [see also Parry, 2004]). Further, Harrison argues that liability can ground a better redistributive project in large part because the terms of compensation are decided upon and administered collectively or publicly (that is, by government agencies and elected legislators rather than through private contracts) (Harrison, 2002). Following legal scholar Carol Rose, she argues that this approach 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 legal 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 USA and more broadly. In their increasingly well-known 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 & Winickoff, 2003).

There are many more examples of novel approaches to biobank and bioscience governance (see Tutton & Corrigan, 2004; Jasanoff, 2005), but the examples listed here are sufficient to make the point. The question of how to recalibrate takings and givings in the domain of bioscience has generated an intriguing array of imagined collectives: government tribunals convened to determine and administer liability rules, patient advocacy groups formed to effect a kind of ‘collective bargaining’ in the research process, charitable trusts grounded on fiduciary relations. These entities are designed to take charge of projects of redistribution; they are grounded in a critique of the gift and a refusal of property; and they require the creation of representative agencies which are, *by definition*, both ‘collective’ and collectives.

As some North American ethicists declare or assume the 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, a site of newly intensified forms of privatization, provoke such a riot of collectivization?

Benefit-Sharing as Risk-Sharing

The answer to that question might well lie in a consideration of the distribution not only of benefits, but of risk, and here bioprospecting offers some valuable lessons. I have entertained a few possible characterizations of benefit-sharing, from a renovated form of exchange to a site for contest over the role of the state, public agencies, the private sector, and associations – those famous ‘groups between’ – as sites of political representation and as agents of distribution of resources. There is a third way of thinking about this new idiom benefit-sharing, which is intimately tied to the first two. Like corporate social responsibility, the privatization of social security and healthcare, and other neoliberal projects that have taken hold across Latin America, the UK and many parts of Europe, and the USA (and elsewhere), benefit-sharing is also, foundationally, a form of risk-sharing. In many of its manifestations, it privatizes and segments projects of distribution and allocation. And insofar as the production of benefits often depends on the emergence of a profitable product, it exposes such allocations to the fickleness of pharmaceutical and biotechnology markets.

I mentioned, above, that we might think about this question of risk-sharing in terms of healthcare systems, the rights of the many, and the entitlements of the few. It is a matter that comes into play in the arena of bioprospecting as well. For in some contexts benefit-sharing agreements have literally arrived 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, in the ICBG project discussed at the outset of this essay, the groups that the lead Mexican ethnobotanist chose as some of his potential benefit-recipients were organizations that had first been established through a government program (Solidarity) established by then-president Carlos Salinas de Gortari in the early 1990s, meant to soften the blow of the North American Free Trade Agreement on rural producers. When these government funds dried up, the Latin America ICBG bioprospecting program literally stepped into the breach, as project directors in Mexico hoped to use prospecting project funds and future benefits to rejuvenate some of these small-scale enterprises. It is of no small consequence that this latter prospecting project, like the majority of those with which I am familiar *and* like the government project that preceded it, has not generated substantial benefits. In fact it was canceled in the fall of 2003, before any pharmaceutical products came close to hitting the market. The speculative nature of such promises of benefits-returned recalls, indeed echoes, the tentative idea advanced by Jon Merz and colleagues to create a 'subject-class' stock in biotechnology ventures related to a particular trial or research effort, in which benefits for participants would be tied directly to the uncertain promise of bringing new products to market.

I will end, then, with a 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 and its participants, in a particular way. Does it matter for my account 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 more than 10 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 draws my attention to 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 have argued in my work on bioprospecting, benefit-sharing is not simply the downstream supplement its architects hope it will be: an added-on act of givingback 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. Thus 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 and an increasing range of non-monetary but

undeniably material benefits. The constitution and relative power of indigenous Aguaruna associations in Peru shift seismically with the speculative promise of benefits on the horizon (Greene, 2004). Efforts to develop new structures of biobank governance or compensation arrangements for tissue donors are prompting some fascinating efforts to reassert the importance of public oversight and collective decision-making and allocation of resources. Together, these developments give us a sense of the heterogeneous forms of collective, political sociality that are required and requested in efforts to rewrite the social contract that is biomedical 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 Anthony Giddens’ infamous Third Way, or the self-recognizing 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 as such. While they might in certain circumstances emerge from patient or indigenous activist demands, just as often, these are collectives that are being called into being by the research institutions charged with brokering access to patients, resources, and benefits in the first place. And they put on display questions that are highly active in other domains of political and social life, such as struggles over the role of the state, philanthropy, and the private sector in allocating resources; questions about the relationship between entitlements and rights; and perhaps most vividly, questions about how new forms of privatization seem to give rise to a range of ‘public-izations’ or processes of producing collectives, the implications of which are far from self-evident.

In the end, I suppose my own form of collectivization is in motion here, one that refuses to see benefit-sharing as an answer to the problem of unrecognized interests and insists instead that we use benefit-sharing to open up a host of unanswered political questions about contemporary processes in which forms of political representation and modes of allocating resources are very much a site of struggle. In the proliferation of calls for a new ethic of benefit-sharing, we can see some of the ways in which political legitimacies are being configured – in some ways and not others – in the name of a science that can and must give back.

Notes

This paper has had many lives and the benefit of many interlocutors, all of whom I thank and none of whom bear responsibility for the final outcome here. I would like to thank in particular my colleague Marc Stears of the Department of Politics at the University of Oxford for incredibly generative collaboration and exchange. I am also indebted to Joseph Dumit, Nikolas Rose, Sharon Kaufman, Katherine Liddell, Bronwyn Parry, and Cassandra Shaylor; and to colleagues at the Universities of Cambridge, Manchester, Harvard, Chicago, and Yale, all of whom have entertained various versions of this essay and whose comments, critiques, and suggestions have been invaluable. Finally, I thank Sergio Sismondo and Michael Lynch of *Social Studies of Science* and three anonymous reviewers for their incisive and thoughtful engagement.

1. See <<http://www.bioethics.upenn.edu/prog/benefit/>> (last accessed 14 August 2006).
2. On the various permutations of the notion of the 'modest witness' – the credible spokesperson(s) who could mediate between the private space of the laboratory and the public space of the polity – see Shapin & Schaffer (1985), Latour (1993), and Haraway (1997).
3. Convention on Biological Diversity Decision VI/24, Access and benefit sharing as related to genetic resources. Available at <www.biodiv.org/decisions/default.asp?m=cop-06&d=24>.
4. Funded by the NIH, the National Science Foundation, and, initially, the US Agency for International Development, the ICBG program began in 1993 and has supported a wide range of benefit-sharing projects, all linking US academic researchers to developing country collaborators on the one hand, and drug or biotechnology companies, on the other. With this program, the NIH infuses a longstanding legacy of publicly funded 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 et al., 1991; see also Reid et al., 1993). For information on the ICBG program see Timmerman (1997) and Rosenthal (1997).
5. Much to the NIH's discomfort, the participating Mexican ethnobotanists argued that it is counterproductive to try to trace benefit-sharing claims back to one bounded community; medicinal plants, they argued, simply don't work that way in Mexico.
6. In Mexico, there has been no national regulation in place regarding bioprospecting contracts – a detail to which many activists point when they say that in fact all bioprospecting agreements are illegal by definition. At the same time, indigenous struggles over sovereignty, self-determination, and land rights – always a powerful question in contemporary Mexico – have remained incredibly tense following the advent of the North American Free Trade Agreement (NAFTA) in 1994. This combination has made participation in bioprospecting contracts a politically risky prospect for Mexican scientists.
7. I thank Joe Dumit for generative conversations on this point.
8. Medical anthropologists such as Arthur Kleinman (1995), communitarian ethicists such as Daniel Callahan (2003) and Michael Parker (1999), and feminist ethicists such as Susan Wolf (1996) have been at the forefront of more than a decade of powerful challenges to this model from within the field of ethics itself as well as from its margins, to use Kleinman's place-marker.
9. See, for example, Pálsson (2002) on the definition of *the* Icelandic gene pool.
10. In a parallel argument, Nikolas Rose and Carlos Novas (2004: 456) note that whether from 'above', as in state initiatives, or from 'below', as with patient activism, citizens are being actively transformed into 'a potential resource for the generation of health and wealth'.
11. 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 (Gregory, 1982; Strathern, 1988).
12. Cited in Gledhill, 2001, note 1.
13. The difference between Titmuss' language of the right to give and the social state of *his* 1973 Britain, and Merz, Kaplan, Cho, and Magnus' portrait of stakeholding participants in the research enterprise of *their* late 1990s USA, could not be more stark. And, instructively, sociologist Richard Tutton has shown that the UK's primary bioethical gatekeeping institutions (specifically, the Nuffield Council and the Medical Research Council) make ample recourse to Titmuss' notions of gift, altruism, and now, *genetic* solidarity in their discussions of what to do with the question of giving and

getting where human tissue banks are concerned (Tutton, 2004). 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 asymmetrical template of who can – and who cannot – derive profit from human tissue.

14. 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.

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