
FOR ALL

Banking (on) Biologicals

Commodifying the global circulations of human genetic material

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I will use two controversies as starting points for this analysis. The first is a court case, *Moore vs. the Regents of the University of California* (1990; henceforth the *Moore* case), and the second is the controversy surrounding the patenting of DNA sequences. In the former case, John Moore, a patient afflicted with hairy-celled leukaemia, had his spleen cells excised. The researchers belonging to the University of California were able to convert these cells into a unique cell line (which they named Mo, after Moore) and were able to patent the cell line. When Moore found out that derivatives of his spleen cells had been made without his knowledge and consent and had been patented, he demanded a share in the property rights. The case was finally decided in the California Supreme Court, which while upholding Moore's claim that the UC researchers had shown a breach of fiduciary duty and had not obtained proper informed consent, denied him any property rights in the cell line, which it was claimed was the researchers' 'invention'. In other words, in the words of critical legal theorist James Boyle, Moore was "the author of his destiny, but not of his spleen" (Boyle, 1997: 107).

In the DNA patenting controversy, however, the exalted status of intellectual property law has looked slightly more crumbly, and many groups with specific interests are trying to devise strategies to get around IP in these areas.

Both of these controversies surround the ownership of human biologicals,[1] in an era in which 'biological' increasingly functions as a noun. The general moral tone that inflects these controversies – and that is particularly stark in institutionalised bioethics discourse – is that the human biological should be 'respected' by being kept outside the realm of commodification.

There is, however, a key difference between the moment of *Moore* (1990) and the current controversies around DNA patenting a decade later, because in the intervening years it has become increasingly easy to *informationalise* human biologicals. Therefore, the controversy surrounding the patenting of DNA sequence information is essentially about the ownership of genetic *information*. Now why is this significant?

Actually, this difference is often not seen as significant, and sliding over this difference is not without consequence. A recent *60 Minutes* show on American TV, for instance, explored DNA patenting and critiqued it as something that horrible biotech companies were doing in order to stake property claims on something that is supremely human and for that reason outside the realm of commodity circulation. Now, if genes *are* information – which is what molecular biologists and bioinformaticians tell us – then patenting information about our genes is equivalent to patenting our genes. But is it really? It is important, I will argue, to tease out the difference between the patenting of human biological *materials* and human

biological *information*. In other words:

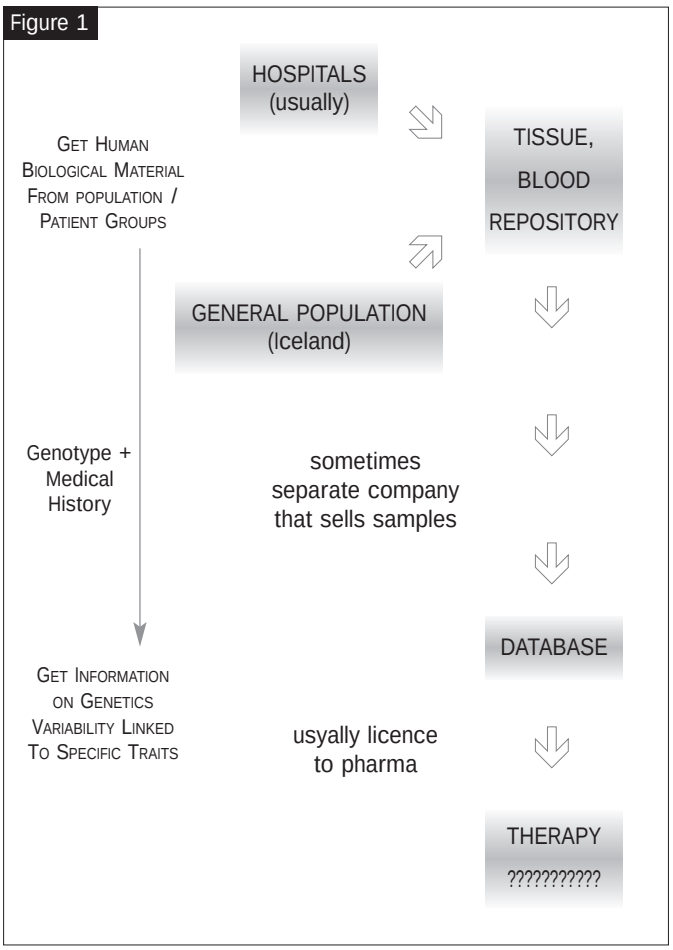
> *Human genetic information is a new type of human biological material that the genomic revolution has made increasingly accessible to annotation and analysis.*

Let me tease out further the different social lives of material and informational biological. Even though these are different 'things', a continued relationship exists between them. This relationship is primarily one of *temporality*. Biological information helps to rationalise wet lab experiments. Therefore, one can use bioinformatics in sequence homology searches in order to determine the probable function of a protein encoded by that particular sequence. The tissue from which information has been extracted then has two functions: it could serve as a continued 'repository' of future information whose extraction isn't even anticipated at the time of the initial experiments. Further, there is often a need to go back and do wet lab experiments on these tissues to actually validate what the information from the tissue suggests about molecular activities within the tissue. In other words, information is detached from its biological material originator to the extent that it does have a separate social life, but the 'knowledge' provided by the information is constantly relating back to the material biological sample. The database plays a key intermediary role in the transition of 'information' to 'knowledge': in this case specifically knowledge that is of relevance to therapy. It is knowledge that is always relating back to the material biological that is the source of the information; but it is also knowledge that can only be obtained, in the first place, through the extraction of information from the material biological. The abstraction of information away from the material biological has a very specific function in making therapeutically relevant knowledge. This is also why it is so easy to intuitively conceptualise the generation of information as 'inventive', and therefore ownable.

Therefore, it is important not to collapse analyses of human biologicals into one category without teasing out the different (if related) social lives of material and informational biological.

What is really new here is less the fact of human genetic information as something that can be obtained, accessed and made 'thingly', as much as it is the sheer volume of information that is now available. At the same time, this is also not something that is synonymous with other types of human biological material, such as the cell lines that were patented in *Moore*. The question to be asked is how different forms of biological – material and informational – *interact*, and how overlapping or different the politics around their respective ownership is.

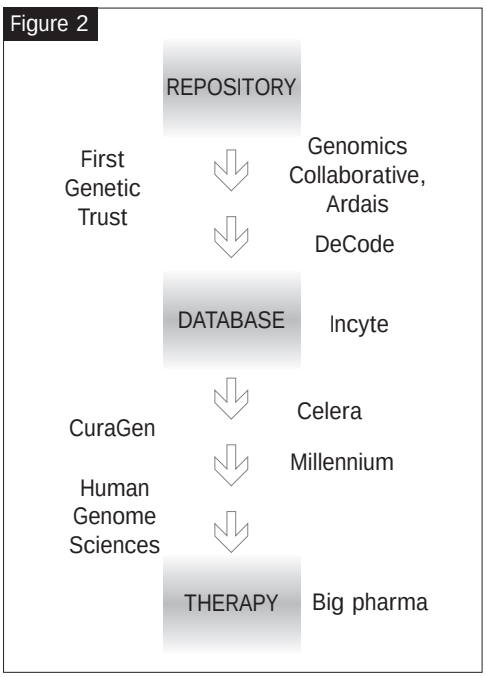
The nature of interaction depends on the type of work that is performed in different cases. The working draft sequence of the human genome that was published in June 2000, for instance, does not document genetic *variability* between individuals and populations, which is of increasing importance in generating information relevant for diagnostic and therapeutic development. For that, one needs DNA from different individual, patient or population groups. The development of, for instance, pharmacogenomics or personalised medicine, which many people claim is the ultimate aim of genomics, is vitally dependent on getting large collections of DNA samples (usually obtained as blood samples, occasionally as tissue samples depending on the disease being focused on). The market terrain that manifests this logic is represented in Figure 1.



Now in this model of genetic research, you obtain human biological material from different, often clearly identified, patient or population groups that are strategically selected, and then genotype them (i.e. find out their genetic sequence). Through such large-scale analysis, especially when situated across multiple populations or patient groups, it is possible to obtain information on that genetic *variability* that centrally underlies specific traits or diseases of interest. The human biological material – *not* information – is usually obtained from hospitals with which researchers draw up specific agreements, though other sources are also occasionally tapped. The Iceland-based genomics company DeCode Genetics, for instance, obtains material from the general population. That material is stored in a tissue repository of some sort. These repositories could be within the company that is planning to

perform subsequent research (as it is in the case of DeCode), or in a public domain tissue collection, or, with increasing frequency, in specific companies who base their entire business models on serving as such repositories. The information that is generated from this material is often converted into databases. These databases are (or so it is hoped by the companies developing them) the precursors of therapy. In an ideal world, the company that generates the database would like to hold the information and use it in its own drug discovery programme. In reality, taking drugs to market is so heavily capital intensive that most database companies license their information to big pharmaceutical companies (again, in the case of the Icelandic example, you see that DeCode has licensed its database to the multinational pharmaceutical giant Hoffmann-la Roche). In this way they try to ensure that information pays off. Now the key footnote in Figure 1, which I will get back to later, is that genotyping alone is not enough to generate meaningful information about the genetic basis of disease: *there is an absolute importance of medical history that can be correlated with the genotype. It's only in the correlation of the two types of information that true meaning can be extracted.*[2] Having in addition information about family medical history is even more valuable, but is very rare except in cases like Iceland. Now the dream for any company that is indulging in this business is that they can do all three of the above steps: collect the DNA, generate valuable information and then develop a drug. In reality, as I've already mentioned, different companies end up concentrating their business models on specific points of this value chain. Some examples of this are shown in Figure 2.

Figure 2



Therefore, you have companies like Genomics Collaborative and First Genetic Trust, which are (at this point at least) primarily DNA repositories. You have DeCode, which is a DNA repository but is using that repository very much as a means to develop its own database reflecting the genetic information of the Icelandic people. Then you have the archetypal database companies, what I call 'first-generation' genome companies that sprung up in the heart of the race to sequence the human genome. Therapy is still very much the domain of big pharmaceutical companies, though there are some older biotech companies such as Genentech that have developed drugs that might be called 'genomic', though these companies were not making databases as part of their business model as Incyte or Celera were.

Controversy around DNA patenting has really only involved the part of the value chain that leads from database downstream to therapy. However as I hope is clear, issues surrounding ownership that most closely resemble the *Moore* controversy have more to do with the part of the chain between repository and database. The field upon which intellectual property debates in biotechnology take place is framed by these two sets of debates. Before I move on to the latter set of issues, I'd like to briefly outline the actors in the DNA patenting controversy and mention what each actor's stakes are.

Very briefly, one could say that there are three groups that oppose DNA patenting. The first are public researchers, who believe that information should be in the public domain. This is both for reasons of logic (generating sequence, they say, is not particularly inventive), and of ideals (an adherence to a certain Mertonian ideal of communism, as reflected in conventions that involve depositing sequence information into a public repository before it can be published by a journal). It must also be remembered that the American state through the National Institutes of Health (NIH) has been a major enabler of private research. Further, the NIH itself has a historical relationship to gene patenting that it would rather forget, having burnt its fingers trying to patent DNA sequences from brain tissue in 1991 (see Cook-Deegan, 1995: 311-325).[3]

Then there is the general public, at least that section that is agitated about DNA sequences getting patented, and who get represented through media interventions like the *60 Minutes* show I mentioned earlier. This type of opposition seems to stem mostly from a gut ethical or moral opposition to the idea of human genetic information being in the realm of commodification. Such a position, as I've tried to argue until this point, does not make much distinction between material and informational biological – human DNA information, in this point of view, becomes 'living matter' in the same way that cell lines do.

The third group that is opposed to patenting DNA sequence information however is in my opinion the most intriguing, and those are pharmaceutical companies. As is evident from the value chain that I outlined earlier, database companies are the ones who try and patent DNA sequence information so that they can sell/license it. Pharmaceutical companies usually have to pay upstream licensing fees and subsequent royalties on any therapy they may discover to these database companies. They would, therefore, much prefer information to be accessible in the public domain. Therefore, even public/private debates are over-coded by corporate fights. In other words, and this is crucial:

What distinguishes the genomics/drug development marketplace from, say, the software industry is its peculiar upstream-downstream terrain. Drug development is such a capital intensive process that there are very few companies with the muscle to actually take drug to market.[4]

Remember, also, that none of the DNA sequence patent debate touches upon the desirability or otherwise of 20-year drug patents, which are still unthreatened. Therefore the SNP consortium, which is an alliance of public researchers and 10 of the world's biggest multinational pharmaceutical companies to keep information of nucleotide-level genetic variation in the public domain, is very much in the interests of the big pharma partners as well. (Of course, it is often projected that big pharmaceutical companies are entering into willing alliances with public researchers and relinquishing patent rights on DNA sequences in order to facilitate cheap, fast and easy flow of information towards therapy. This is not untrue; what gets hidden from such rhetoric is that it isn't these guys who're in the business of leveraging sequence patents for profit in the first place. See Sunder Rajan, 2001 for an elaboration of this argument). What I want to emphasise at this point is that the different approaches to DNA patenting between, say, Hoffman-la Roche and Celera is not because Celera is inherently evil or a nasty little spoiler while Roche realises the benefits of free downstream flow of information. It is because pharma companies and database companies occupy fundamentally different market niches that dictate how they approach DNA patenting. All companies are aggressive protectors of intellectual property *when it benefits them*. It is this particular upstream-downstream terrain that distinguishes the drug development industry from, say, the Internet or finance industries.[5]

For the rest of this paper, I want to focus on ownership issues that arise when one deals with the first half of the value chain I showed earlier: the bit concerning itself with creating databases from corporate DNA repositories. What sorts of ownership barriers underlie the business models of the companies that concentrate on this part of the value chain? I will specifically talk about one company, a commercial DNA repository based in the north-eastern United States that I shall refer to as Repository X (Rep-X).[6]

In its corporate description, Rep-X calls itself "a functional genomics company with a comprehensive, clinical approach to discovery, focused on developing high value, proprietary intellectual property for its own account and in collaboration with major biopharmaceutical companies. Rep-X maintains the [Rep-X proprietary repository][7], an unparalleled, large-scale resource of clinical research material, including human DNA, serum and snap-frozen tissue samples, linked to detailed medical information collected from patients worldwide. To date, Rep-X has recruited more than 100,000 patients in its effort to build the [Rep-X proprietary repository], and collections continue".[8] In other words, what Rep-X wants to become is the world's largest commercial DNA repository, collecting DNA samples from all over the world, genotyping them and then leveraging them for profit.

Now obviously a business model such as this can be deemed by many as ethically somewhat fraught, as indeed the controversies over DeCode and the Icelandic genomic database have shown (though the key differences have to be borne in mind here: two of the major reasons why DeCode is so controversial is because they presume consent rather

than obtain informed consent to use medical information; and secondly, because they have been given exclusive rights for their database by the Icelandic parliament. Rep-X does adopt an informed consent procedure and, in theory at least, any company could base itself on Rep-X's business model and compete with them for sample collection). So clearly bioethics is a key area in which Rep-X takes an interest, which is not unusual for a biotech company these days. Indeed, Rep-X has its own in-house bioethicist, a bioethicist being a peculiar breed of individual who professes 'expertise' in the ethical issues that surround new biotechnologies. In fact the CEO of Rep-X says of hiring bioethicists: "I'm surprised more companies don't do it. It doesn't cost us anything, and in the end it may save us [money, time or reputation]. I mean, the whole idea of it is so reasonable. We've always said that if we are going to be on the front page of the *New York Times* we'd better make sure we get it right".[9]

Rep-X haven't yet made it to the front page of the *Times*, but they have made it to the business page of the *Boston Globe*, testifying to the enormous amount of generally favourable publicity they have been getting in business and investor circles in the US. The *Globe* article is typically celebratory, and paints a picture of dynamism, speed and incessant progress, none of which is an unusual character sketch of a young biotech company. A quote from this article: "When the FedEx driver rings the bell on the loading dock at [Rep-X], it's a call to action. The driver unloads bundles of special envelopes marked with the biohazard symbol: fresh samples of tissue and blood from patients nationwide. Within minutes, technicians scurry to open individual plastic kits. Glass vials of blood, each identified only by a bar code, are quickly scanned into the computer – like a giant grocery checkout in reverse. Processing the samples is a carefully choreographed blend of tedious hard work and blazingly fast robotic automation" *(Boston Globe*, August 22 2001). And so it goes on: the combination of speed and genius combining to create value from a novel business model, the seamless rhetoric reflecting the seamless operations of an aggressive young company.[10]

Now the big 'ethical' issue that Rep-X confronts, à la *Moore*, is not the fact that it can own samples, but the fact that it should collect them properly – as their CEO suggested in the quote earlier, 'doing it' isn't the question as much as 'doing it right' is. In other words, like the judges who constituted the majority opinion in *Moore*, Rep-X is most worried about getting proper informed consent. It knows that in the US at least getting exclusive property rights on the samples doesn't really constitute the bottleneck. This is reflected in Rep-X's fascinating statement of what it calls "Rigorous Ethical Standards", which states: "[Rep-X] is committed to maintaining the highest ethical standards possible, and to that end, meets quarterly with a distinguished Bioethics Advisory Board that has been invaluable in developing innovative solutions to the range of ethical problems posed by genetic research. In addition, [Rep-X] has created a proprietary system for anonymising collections while ensuring data quality and protecting patient confidentiality. Informed consent and patient rights are key to [Rep-X]'s operations, and ensure sample quality while maintaining pristine ethical standards. Working with international leaders in the area of informed consent for genetic research, [Rep-X] has developed consent procedures appropriate to the repository context".[11] Not only does Rep-X, in statements like this, espouse itself as the embodiment of ethical practice, it also sets up the idea that an institutionalised bioethics provides exper-

tise that can transcend national boundaries and contexts, in the same way that the genetic samples Rep-X collects do. Indeed, Rep-X's statement is quite typical of the disclaimers that are central to many of the companies that occupy the part of the value chain between repository and database, and concerns itself with proper informed consent procedures for sample collection, privacy and confidentiality. Of course, what is notably missing in this statement is anything to do with ownership rights, which, as in the case of *Moore*, are deemed non-negotiable. This is because it is the company that's doing the genotyping that's deemed to be the 'inventive' work; where samples come from merely constitutes source, which is always written out of intellectual property agreements.

Unfortunately for Rep-X and the retinue of 'expert' bioethicists who profess transnational and universal problem-solving capabilities, the expertise of institutionalised bioethics, professing as it does primarily American (and sometimes European) codes for ethical governance – such as we worry about informed consent and privacy, but sharing ownership is not even an ethical question – doesn't translate very well into other socio-political and geographical contexts.[12] My last set of points therefore is going to have to do with the friction that Rep-X's seamless rhetoric encounters in the practical context of collecting genetic samples from India: a friction of course that is completely left out of the narrative that institutionalised bioethics, the business press and Rep-X's own public relations apparatus construct for it.

India occupies a particularly interesting and ambiguous space in global technoscience writ large, a space that is particularly accentuated in areas relating to biotechnology and drug development. At one level very much a Third World country with some of the lowest human resource indices in the world, India has always privileged science and technology as levers into globally competitive playing fields. Presently, India's technoscientific establishment is undergoing a profound period of change, as the institutional socialist model of primarily state sponsored R&D is giving way to a more market oriented approach. However, some of the most aggressive market players in Indian biotech are not companies, which are still by and large reticent and risk-averse, but Indian public sector labs.

Genomics is an area that the Indian government has been particularly interested in. India did not get into the Human Genome Project in the early '90s, a fact that its scientific policy establishment was ruing by the mid-'90s when it became evident that genomics was where the action – and the fame and money – were at.

Public labs in India have now become enthusiastic participants in genomics and population genetics, and are helped by the fact that Indian populations are, for a number of reasons, deemed to be very good candidate populations for genetic studies.[13] Therefore, they see Rep-X's sample acquisition in a very different light from Rep-X.[14] They maintain that Rep-X's samples are worthless, even if extensively genotyped, without detailed medical records. These medical records are collected along with the samples from Indian hospitals. Therefore, this argument goes, the Indian hospitals should have a share in the IP. Indeed, some American companies do draw up extensive legal arrangements with the hospitals they obtain samples from, such as Ardais, which has an extensive agreement with the Beth Israel Deaconess Medical Center in Boston. This argument therefore says that if Rep-X

shares IP with Indian hospitals, it can have all the samples it wants. But if it doesn't, then it is theft. What complicates this analogy is that many of the best known research hospitals in India are public institutions, whereas in the US most such hospitals are private and function as corporations. Therefore, this argument of the Indian state paradoxically frames the state as itself a corporate entity. This is very much in keeping with a post-1990s ideology of economic liberalisation that has been prominent in Indian elite and policy circles and whose idea of India is as India Inc. With Rep-X so far unwilling to draw up IP sharing agreements with Indian hospitals, all the samples that they have collected from India since October 1999, under the authority of the Indian Council for Medical Research (ICMR), have been prevented from leaving India.

Who could have guessed from the *Globe* that a significant outcome of Rep-X's "careful choreography" involves rotting blood samples in a Third World customs shed?

To summarise then:

> Ownership debates relating to human biologicals tend to confuse the ownership of human biological *material* and human biological *information*. The difference between these two forms of ownership is not something that is in the intangible realm of bioethics, but is directly related to different upstream business models that are trying to realise value off of different biological things (that often, indeed, translate into different types of biological information).

> All of these issues must be situated in the understanding of the drug development marketplace, which because of the capital intensive nature of the enterprise, has a very few, very large companies that are positioned to actually take drugs to market. Most of the upstream innovation therefore leads ultimately to licensing agreements with big pharma companies. Therefore, it is much harder to envision a situation in drug development where upstart companies take on Microsoft-like giants. What they can primarily do is encumber the marketplace for big pharma, by developing proprietary knowledge that big pharma has to license.

> When the proprietary 'stuff' that is at issue is genetic information that might otherwise have been in the public domain, it is obviously as much in the interests of pharmaceutical companies as of public researchers to remove the playing field of those patents. Also, the notion of the 'dubious' patent here is very much framed and limited by an ideological notion of research (drug patents, and their advisability or otherwise, aren't even deemed an issue). Therefore you see arrangements such as the SNP consortium, which sees the alliance of public researchers with big pharmaceutical companies to facilitate unfettered release of genetic information into the public domain.

> Business models dealing with biologicals further up the value chain, between DNA repository and database, however, have a different set of ethical issues and ownership politics tied around them.

Bioethics, which is supposed to be providing the space for ethical and political discourse, does not believe that central to these issues is ownership – as an institution, it is more concerned with informed consent and privacy issues, just like the judges in *Moore* were.[15]

There is, however, a lot of varied resistance to IP laws as they exist surrounding the ownership of human genetic material, and this resistance takes various forms depending on the stakeholders involved.[16] The resistance from the Indian state is of a particular order. It doesn't want IP because it thinks source should be valued. It wants IP because it realises that generating medical records is part of the inventive procedure. In fact at first sight the argument that it is public *hospitals* and not *patients* (which is what a model such as PXE International's might suggest) that should share in IP might seem rather peculiar. Nor is it the Indian state as represented by the ICMR that wants to share IP, as an institution that can distribute those rights through *all* hospitals, regardless of where samples are obtained, as public good. All that the ICMR wants is that the same market principles for licensing and ownership sharing that get applied in arrangements between hospitals and research institutions in the West be reapplied in the Indian context – a position, as I mentioned above, that can be deemed problematic both from the point of view of a distributive justice argument and in the way a public institution frames itself as a corporate entity.[17] In the global (South à North) travel of genetic material, the South/Third World gets framed as 'source' – and this is of course a framing with a colonial legacy, that even anti-imperialists in countries like India buy into, often legitimately. The Indian argument here is that Rep-X taking samples from India and patenting it is not colonial expropriation, but industrial theft.

A version of this paper was presented at the conference Wizards of OS: Open Cultures and Free Knowledge, held in Berlin, October 2001. Many thanks to the conference organisers, as well as Christopher Kelty, for their invitation to present this work. I have also benefited greatly from discussing this paper at the Science, Technology and Society writing workshop at MIT. Thanks especially to Alexander Brown, Joseph Dumit, Shane Hamilton and David Kaiser for extremely provocative and useful comments.

NOTES

1. Patents can be taken out on DNA from any species, but I stick to the case of human genetic material for this paper.
2. One could conceptualise this by the relationship: R_X Genomic Info = genetic material + genotype information + medical information.
3. The person who filed that patent application was actually J. Craig Venter, CEO of Celera, which controversially raced the public Human Genome Project to sequence the human genome.
4. One might think, however, that the state, were it so willing, might have the muscle to bring drugs to market. Historically however the state, and not just in the United States, has been very good at initial capital outlay that enables the development of private industry, but has been very bad at successful long-term execution on capital intensive projects. Therefore, while the idea of a 'public-sector' pharmaceutical company might be tempting to those who believe that the state should invest heavily in the development of accessible therapeutics, this is likely to remain out of even the spectrum of options that states generally explore. Further, in the United States, there exists an extremely strong pharmaceutical company lobby in Congress. Therefore, the US state has very close relationships with big pharma.
5. The analogy of the upstream-downstream terrain of drug development with the software market is interesting for me to think through further. I have suggested that the capital intensivity of drug development makes it very unlikely that small biotech companies will ever really compete with and displace big phar-

maceutical companies. Such a capital intensive environment as a competitive advantage for large companies doesn't really exist in industries like the software industry. In other words, I have suggested that the very *nature* of drug development makes it that much harder to alter the fundamental power relations between small and big companies. Having said this, the fact remains that in the software industry, few organisations have seriously tried to go up against Microsoft's core business. There have been many that have tried to compete with one or two products or services that Microsoft has offered, but the only significant challenges have come from those companies that have fundamentally tried to change the rules of the game (such as Netscape or AOL). The costs of bringing any big product to market, regardless of industry, are likely to keep the number of competitors low. Nonetheless, the time the biotech industry was just beginning (in the late '70s) was the time a little start-up called Microsoft was challenging such established computing giants as IBM and Wang. Even if Microsoft has an impenetrable hold on the software market today, there has historically (as seen in Microsoft's own case) been the room for the sort of emergence of a small company into a giant corporation that has just never happened in biotech. I am grateful to Alexander Brown for conversations that have helped me think through these parallels.

6. I have wrestled with the issue of whether to name this company or not, and am still not sure that my decision to keep it anonymous is the correct one. These are dilemmas that are of some consequence in thinking through methodological questions surrounding the ethical choices that one makes while doing corporate ethnographies.

   Donna Haraway has said that one reason why she didn't do any interviews for her book *Primate Visions* (1989) is because she wanted to be angry and didn't want the entanglements of the interview relationship to get in the way of writing what she wanted to. Joseph Dumit ponders this very seriously in his recent work on venture science (still unpublished), where he names two biotechnology companies and has therefore consciously decided to avoid interviewing people at these companies. In this case, however, I had already interviewed two people at Rep-X (one employee and one manager, one on-tape and one off-tape) before I learnt of the company's controversial situation in India that I discuss in this paper. At no point in this paper do I draw upon these conversations. As Dumit has shown, it is both legitimate and a challenge to do corporate ethnography by working from the public record in order to reserve the right to 'tackle' certain actors. While that is precisely what I have done in this paper (using not just the public record, but public documents that Rep-X has had a significant hand in 'spinning' to its own advantage), the problem of how to 'forget' my conversations at Rep-X is a lingering one. I have decided to keep Rep-X anonymous until I have resolved it for myself.

   This is, as much as anything, an acknowledgement that anthropology is different from journalism, and one of the lines of difference is the relationship with informants. Journalism is adversarial by nature: the work is to 'get' a story out of a subject, even if there is a long-term relationship involved. The challenge for an anthropology such as this is to be ethical and non-adversarial, which is not to say non-critical. At the end of the day, anthropologists write, in part, to their subjects, not just to their colleagues and beyond.

   Corporate ethnography involves writing about what is fundamentally a culture of secrecy. I take inspiration here from Hugh Gusterson's work on nuclear weapons scientists (Gusterson, 1996), which shows quite clearly his fascination by how and why things get made secret, without necessarily feeling the obligation to make public what the subjects want kept secret. This is precisely the opposite of the investigative journalist. On a basic level, the journalist wants the 'truth' that is 'out there', while the anthropologist wants something like the subject's truth, or truth in Foucault's sense of "the system of ordered procedures for the production, regulation, distribution, circulation and operation of statements… linked in a circular rela-

tion with systems of power that produce and sustain it" (Foucault, 1980: 133).

Many thanks to Joseph Dumit for a series of conversations and correspondences on this dilemma, many of which I have directly borrowed from in making my argument for anonymising Rep-X here.

7. Name of repository anonymised.
8. This quote is obtained from the Rep-X web page. However, in order to preserve anonymity, the exact citation cannot be provided.
9. This is also a quote linked to Rep-X's web page, and therefore will not be cited in order to preserve anonymity.
10. I am particularly intrigued by the way in which this article makes DNA sample delivery sound like groceries being delivered. This could, from the tone of the article, be a description of such online grocery stores as homeruns.com or namaste.com. This is not merely an interesting discourse: it is, I believe, a strategic one. After all, making controversial activities seem mundane is key to naturalising them.
11. Yet again, I will not provide the exact citation, which is taken from Rep-X's web page.
12. The question of why bioethics concerns itself so little with questions of ownership is an interesting and important one to address. A major reason is disciplinary and pedagogical: institutionalised bioethics, especially in the US, draws largely from analytic philosophy, which engages normative questions much more readily than questions that are more explicitly 'political'. My suspicion, however, is that *Moore* has served as more than just a legal precedent: it has further served as a normative precedent, that suggests somehow that ownership issues are 'settled'. This is why challenges to intellectual property regimes come much more often from that messy and unpredictable space of the public domain, and through the messy and unpredictable routes of politics, than through institutionalised spaces that, at some level, do exist to channel and regulate this messiness through the 'sanity' of expert mediation. In other words, it isn't just the *content* of bioethics that I find problematic. It is the bioethicists' mediation in such debates *as experts*, to the exclusion of other participating voices, that makes institutionalised bioethics such an undemocratic institution, even when it manages to be an 'ethical' one. The question that is left hanging for me then is what a genuinely transnational bioethics would look like, since I do believe that biotechnology as a global regime needs transnational, democratically accountable systems of governance and regulation. One direction to look for this is towards patient advocacy groups such as PXE International, that I mention in a later footnote.
13. Of course, neither of these is obvious or intuitive outside the constantly expanding rationality of population genetics as a discipline and enterprise that discursively constructs populations as units that 'naturally' exist to be genetically studied.
14. This section is based on conversations with Indian scientists and policy makers. Instead of directly quoting specific conversations, I have summarised their general content, and will keep specific informants anonymous.
15. This institutionalised bioethical position is not hugely different from the positions adopted by biotech 'activists' such as Jeremy Rifkin (see, for instance, Rifkin 1998), who fail just as spectacularly to situate their critiques in any way. I am writing as much against this particular, unsituated mode of 'activist' antagonism towards biotech as I am against institutionalised bioethics, or certain biotech corporate practices.
16. You have, for example, the Human Genome Diversity Project, a public project of the NIH, which has met with fierce opposition from Native American groups, who simply do not want to participate in the genetics revolution because they don't expect to be the beneficiaries of it. A very different stakeholder is PXE International, a patient advocacy group founded by Pat and Sharon Terry, who believe they *will* be direct

beneficiaries of the genomics revolution if they can have some control over research agendas. So they have negotiated IP agreements with companies in which they share in the IP – a model that completely overturns an IP rationale that has always valued 'invention' while simultaneously devaluing 'source'. PXE International, however, believes that PXE patients who donate their samples through the organisation are not merely 'source', since the organisation has significant control, through the use of the IP rights, in charting the inventive agenda. See www.pxe.org for more information on PXE International, and the Indigenous Peoples Council on Biocolonialism web site, www.ipcb.org, for a Native American organisation's perspective.

17. The question of what constitutes 'source' and what 'invention' is, of course, a central one in IP debates writ large, and isn't just confined to biotech. Telephone books, for example: what was initially deemed to be public record was claimed to be copyrightable when put in the 'inventive' form of an alphabetical compilation, and the phone book companies won. The question of what, if anything, is distinct in the blurring of source and invention in biotech – other than the obviously different and dramatic political contexts that some of these biotech controversies operate within – is of central importance, and something I'm very much grappling with.

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