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Genomic stuff: Governing the (im)matter of life

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Abstract: Emphasizing the context of what has often been referred to as "scarce natural resources", in particular forests, meadows, and fishing stocks, Elinor Ostrom's important works, including *Governing the commons* (1990) and *Understanding institutional diversity* (2005), present an institutional framework for discussing the development and use of collective action with respect to environmental problems. In this article we discuss extensions of Ostrom's approach to human genes and genomes and explore its limits and usefulness in this field. We argue that while there are radically different contexts and cases and governance regimes still to be debated, what we call "genomic stuff" – genomic material, data, and information – often can best be regulated by modes of stewardship and self-regulation of appropriators. We exemplify this claim by a discussion of gene patenting, the "Genome War", and the so-called HapMap project. The issue of how to best govern the genomic stuff of humans, we suggest, is complicated by the situation that the appropriator and the appropriated can be the same, inviting fundamental questions about politics and ethics.

Keywords: Digital and global commons, Elinor Ostrom, epigenetics, genomic stuff, governance, life itself

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I. Introduction

During the 1980s, several fields of scholarship—in particular, anthropology, ecology, economics, and political science—collectively established a new interdisciplinary domain focusing on the cultures, practices, and institutions associated with the governance of commons (see, for instance, McCay and Acheson 1987). While discussions of adequate approaches to governing resources have a much longer history, especially in political theory, until the 1980s they had rarely been addressed in the context of consistent comparative and empirical work juxtaposing speculation and theory, on the one hand, and actual regimes, on the other. Without doubt, the new interdisciplinary effort to address questions related to the governance of the commons was partly informed by the growing environmental problems of late modernity, including those posed by rapidly expanding human populations, ever more efficient technologies of extraction and exploitation, and the near collapse of entire ecosystems and animal populations, especially fish. Arguably, more than any other single work Elinor Ostrom's book *Governing the commons* carved the new interdisciplinary domain of the commons.

In this article we discuss extensions of Ostrom's work on governing the commons to the governing of human genes and genomes, and explore the limits and usefulness of her approach in this field. We have decided to speak of "genomic stuff" to accommodate, a priori, all aspects of genomic material, data, and information, independent also of the levels of their materiality and meaning. While there are radically different contexts and cases and governance regimes to be debated, drawing on Ostrom's work we argue that genomic stuff can best be regulated by modes of stewardship and self-regulation of appropriators. We exemplify this claim by discussing several cases that have contested and defined rules for articulating public and private interests in genetic and genomic research – gene patenting, the "Genome War", and the so-called HapMap project (HapMap 2010). The issue of the genomic stuff of humans, we suggest, is complicated by the fact that the appropriator and the appropriated can be the same, inviting fundamental questions about politics and ethics.

Emphasizing the context of what is often referred to as "scarce natural resources", Ostrom's work presented an institutional framework for discussing the development and use of collective action with respect to environmental problems and common-pool resources (CPRs), an alternative to both the governance of the nation state and the neoliberal solution of private property and the market. Drawing upon the "new institutionalism" developed by Douglas North and some others, Ostrom underlines the impact and interrelations of social institutions – what anthropologists would be likely to refer to as cultural context. In her words, her book "attempts to combine the strategy used by many scholars associated with the 'new institutionalism' with the strategy used by biologists for conducting empirical work related to the development of a better theoretical understanding of the biological world" (1990: 25).

In her more recent book, *Understanding institutional diversity*, Ostrom (2005: 9) lists a number of cases and contexts for exploring the "building blocks" of

institutions. None of them, however, relates to the context of genomics. Genes are mentioned in the book, albeit in a particular context. Here, Ostrom uses the coding of genes as an analogy for the rules governing institutions: "Genes underlie phenotypic structures in a manner that is broadly analogous to the way that rules underlie action situations. But neither genes nor rules fully determine behaviour of the phenotypes that they help to create" (2005: 30). Genes, then, are taken as the equivalent to the "alphabet of the phenotype of human social behaviour" (2005: 30), not as a resource-base to which equivalent rules and institutions might or might not apply. Do we need specific governance regimes for genomics and, if so, what could they look like?

As will become apparent, much depends on what the reference to the "biological world" pertaining to humans is taken to mean. Should it be seen as a neatly separated and compartmentalized domain, in contrast to society, or should it be regarded as something fundamentally unstable? What exactly is being governed in "biological" commons? To what extent does a classic such as Ostrom's work help to address the "strange" world of genomes? What life itself is understood to mean has been increasingly destabilized in the wake of massive intellectual and practical changes involving a complex array of theoretical and empirical innovations, including those of epigenetics, systems biology, microbiomes, and molecular vitalism (see, for instance, Kirschner et al. 2000; Moss 2003; Franklin 2006; Turnbaugh et al. 2007; Rheinberger 2010). Many recent debates highlight the intimate relationships between genetic and non-genetic factors such as life-style and external stimuli and the ways in which they mutually constitute each other. In light of the profound changes that have taken place in the understanding of genomes and their "environments", to what extent can Ostrom's work, which has tended to focus on more stable domains. be helpful in addressing the problem of governance in this field?

The literature on the management and governance of genomic stuff addresses at last two empirical domains recently carved out by a range of scholars and disciplines. One entails the discussion of the rights and institutions associated with the study of the human genome (see, for instance, Rose 2007) and national biobanks (Gottweis and Peterson 2008), focusing on the extent to which they parallel those of "other" natural resources, an issue we discuss below. The other relates to digital sources and the Internet. To the extent that genomic stuff does not have a clearly bounded corresponding material dimension, it may bear a strong resemblance with digital resources. Thus, the work on the digital commons (Boyle 1996; Greco and Floridi 2004; Coleman and Dyer-Witheford 2007), or the "commons of cyberspace" (Levine 2001), are relevant to consider with regard to the governance of genomics. As Kelty (2008) points out, the arrival of the Internet has generated a culture of free software. He addresses the practical and political meaning of the fact that there is only one Internet: "How is it that the Internet is open in the same way to everyone, whether an individual or a corporate or a national entity?" (Kelty 2008: 306). Like the Internet, genomic stuff – particularly in its form of genomic information – is typically a common-pool "resource that

is neither divided among separate property holders nor managed directly by the state" (Levine 2001: 205).

However, the analogy between the governance of the digital commons and the human genomic commons is not perfect. While the digital commons are, as the term suggests, digital (which implies that with every additional content uploaded to the World Wide Web the resource itself expands), genomics is partly chemical and partly analogue-narrative (e.g. numerical or other representations of genomic data or information in databases or in files). There are many possible scenarios where the "uploading" of new data (e.g. new sequence data into a database) extends the resource itself; however, unlike the digital commons, not *every* activity within the resource extends or changes the resource itself. For example, a re-analysis of a DNA sample – which belongs in the realm of genomic *material* (see below) – in the context of a forensic investigation does not expand the commonly shared resource.

Another respect in which work on the digital commons is arguably not applicable to genomic commons is the notion of self-interestedness. In their paper on the tragedy of the digital commons, Greco and Floridi (2004) argue that the notions of "excessive exploitation or pollution of the commons" (Greco and Floridi 2004: 74) is a notorious problem in the governance of the digital commons:

Typically, each user tends to use all the *bandwidth* he [*sic*] has, without considering the presence or the needs of other users, who are consuming bandwidth at the same time. Each user considers the presence of other users only when there is saturation of the bandwidth, because he is then reminded that other agents are sharing the same limited resources. This is exactly what happens with Hardin's herdsmen (Greco and Floridi 2004: 75; original emphasis).

In other words, "selfish" appropriators – those who obtain the highest utility by using the commons without considering, and acting upon, the needs of others – compromise the quality of the resource and increase its vulnerability; in extreme cases, they destroy parts of the resource (e.g. when they introduce malware or viruses into the system).

While other authors on the digital commons dispute this analysis and argue that the Internet, in many respects, represents a "cornucopia of the commons" (Bricklin 2001) where users' voluntary contributions (e.g. in software development) create "more robust and inventive results than commercial developers" (Coleman and Dyer-Witheford 2007: 935), we certainly also dispute the linear applicability of the selfish user-hypothesis to the field of genomics. It misfits the genomic commons in at least two ways: first, the use of the commons by one appropriator typically does not destroy the commons or diminish its value for other appropriators. There are some exceptions, such as gene patents (see below), and cases such as the scenario that the use of a DNA sample for analysis means that the sample is destroyed in the

¹ For a critique of the assumption of self-interestedness in economics more broadly, as well as of the ignorance of neoclassical economics of the material substrates of exchange, see Pelletier 2010.

process; however this pertains only to certain cases of the use of genomic material, and not to the use of genomic data and information. Second, at the rhetorical level, the field of genomics, as we will see, is permeated with mechanisms of altruism, not selfishness. The scope and power of the notion of altruism, however, is not limited to the merely rhetorical dimension, where genomic information is referred to as the shared heritage of humankind (Prainsack and Naue 2006), but it extends to the level of practices and protocols entailing the altruistic donation of genomic samples, data, and information by research participants and patients (Knoppers and Chadwick 2005; Lunshof et al. 2008), and research funding policies that demand that data obtained from publicly funded research are published in open access databases.

In sum, while recent work, especially on global commons (see below) and digital commons, can fruitfully inform the governance of genomic stuff, due to its particular ontological and material configuration, its governance poses unique questions in some respect. These particular configurations will be the subject of the next section.

It is easy, we may note, to dismiss the notion of "stuff" in this context as it is often used in a pejorative sense to designate relatively worthless material or immaterial things, much like the notion of "junk". However, "stuff" is sometimes used with a very different meaning, conveying a hightened sense of vital importance. Thus, the Middle-English term "stuffe", from which it is drawn, referred to both a person's essential moveable household property and the weapons and food necessary for battle (Harris 2011: 162).

2. Labouring bodies, decoding genes

In the early days of genomic research, the early 1990s, genomic information was seen as a "blueprint" for life (Hedgecoe 1999; Kay 2000), something that would divulge its meaning once its signs had been "decoded". Since then, it has become increasingly unclear, however, what the "book of life" actually consists of. With regard to many diseases and traits, sequence data alone does not say much at all. The genome sequence, it seems, bears closer resemblance to a glass of ink than to a book: the substance with which the letters would be written are there, but they have not yet taken any particular form, and it is impossible to determine what that form would be merely by looking at the ink.² Moreover, it has become clear that the definitions of, and differences between, genetic and genomic data, information, and material are not at all clear cut. If, pertaining to the full genome, genetic data are the letters of the genome sequence – that is, the base pairs representing DNA – then when does this data turn into "information"

² In his *Variation of animals and plants under domestication* Darwin introduced a similar metaphor of the code in the context of generation and heredity, referring to "invisible characters, proper to both sexes ... and to a long line of male and female ancestors ..."; "these characters", Darwin added, "*like those written on paper with invisible ink*, lie ready to be evolved ..." (quotation in Müller-Wille and Rheinberger 2007: 24; emphasis added).

(see, for instance, Gere and Parry 2006)? In other words, when, and by what processes, does it become meaningful?³ In what circumstances does it need to be complemented by non-genetic information to acquire specific meaning, and how does one incorporate these non-genetic dimensions of information into the term "genetic (or genomic) data"?⁴

In addition, as Keller (2000) famously argued, the concept of "gene" is highly unstable, and varies from one discipline to another. For Rheinberger, similarly, the gene belongs to a class of fuzzy "boundary objects" that cannot be assigned a precise meaning; in his view, the usefulness of boundary objects does not rest with a clear definition from the outset: "indeed it can be rather counterproductive, to try to sharpen the conceptual boundaries of vaguely bounded research objects while in operation" (Rheinberger 2000: 221). If the relationship between the term (gene) and the material reality that it signifies (a particular segment of DNA) is not clear cut, what does the term "genetic material" mean? What is the role of annotation in this process? Clearly, the question of in what form genetic (pertaining to the DNA sequence alone) and genomic (pertaining to the DNA sequence, the transcriptome, and the proteome, which consists of RNA and proteins) entities are a "resource" is an important issue, which in turn is related to the question of the difference (and differentiability) between genetic material, genetic data, and genetic information. The use of the term "genomic stuff", we suggest, helps to avoid making strong claims about materiality and informatics.

Historically, the discourse on governance and property has described the characteristics of resource regimes in terms of rather simple binary dimensions: stationary vs. mobile, aquatic vs. terrestrial, biological vs. physical, material vs. intellectual. Along with some other body issues, including surrogate motherhood, organ transfer, and biobanking (Dickenson 2007; Gottweis and Peterson 2008; Hirsch 2010), genomic stuff seems to invite new dimensions and considerations. For one thing, we suggest, with the new genetics, the development of biomedicine, and the expanding production of biocapital (Lock and Nguyen 2010), the very

³ From within the disciplines of genetics and genomics, there may be a straightforward answer to this question: Genetic data become meaningful – and thus turn into "information" – when there is a phenotype associated with it. What we refer to here, however, is a more inclusive understanding of meaningfulness. For example, short fragments of DNA that repeat themselves at a certain genetic locus – so called short tandem repeats (STR) – which are used in forensic DNA analysis assume meaning when translated into a "DNA profile" which is compatible with the format of a database. In this case, no association with a phenotype is necessary for the genetic data to obtain meaning.

⁴ An example of how this ontological ambiguity regarding the terms data, information, and material is relevant in practice is the Genetic Information Nondiscrimination Act (GINA) which was signed into federal US law in May 2001 to prevent certain cases of discrimination based on genetic information, mainly by employers and insurers (Prainsack 2008). The Act defines genetic information so widely that the prohibition of discrimination on the basis of genetic information also pertains to information that was obtained by producing a family disease history, and not by means of genetic tests. Thus, the narrative nature and the necessary selectiveness (one often knows more about some strands of one's family than another, while other relatives may be entirely unknown) of familial relationships becomes folded into the term genetic information.

notion of the "biological world" has been destabilized as nature is increasingly subject to artificial, human, and social refashioning (Rabinow 1996; Landecker 2007; Pálsson 2007). As mentioned above, recent insights from the field of epigenetics – the study of phenotypes resulting from chemical changes in gene promoters (gene areas regulating their level of transcription to mRNA) that are not alterations in the DNA sequence (Stowers Institute for Medical Research 2009) – necessarily complicate the relationship between genetic data, information, and material. Moreover, the possibility of zooming in on the micro-world of cellular material inevitably destabilizes common notions of the genetic and, more generally, the biological. This in turn demands a rethinking of the governance of biological commons and raises important questions about the relevance and applicability of Ostrom's institutional framework to the governance of genomics.

Human genomic stuff, of course, is not only an informatic and material resource for genomic researchers and companies. It is also a highly personal entity, with potentially profound implications for selfhood, health, social relationships, and also data protection and privacy. This adds to the complications of governing genomes: that which is used and appropriated by, for example, scientists to develop diagnostic or therapeutic tools with the goal of improving the health of people, often stems from these very people. In other words, in some situations, the appropriators can be largely – on some level – equated with the appropriated. Even when this is not the case, the providers of the resource, genomic material, data, and information, are active co-producers of the value from which they may later benefit, even if not in immediate ways but by means of higher level of health care, or better drugs, for the society as a whole.

Although this scenario contains elements of the free riders problem, it cannot be reduced to it. Let us assume that of two neighbours, Amy and Tim, only Tim responds to a call to donate a DNA sample and clinical data to a population database used for medical research. As Amy is likely to benefit from the results obtained in research studies drawing on that database as is Tim, she is a free rider. This situation is complicated, however, by the fact that Tim's costs for donating a sample to the biobank are minimal; his travel costs are reimbursed, the pain incurred by the taking of the sample is minimal, and due to a well-conceived governance regime which the biobank devised for itself, the risk to his privacy is very small. On the contrary, Tim gets a free comprehensive health check upon signing up as a research participant. And by donating his DNA and clinical and other data to a population cohort Tim contributes to the representation of those who share his own genetic, lifestyle, and other characteristics in large-scale disease research.

While Tim's participation in a biobank can thus be seen as not posing significant risks or incurring large costs, the question of how one should characterize the conditions of labour in this peculiar and rapidly expanding production regime remains open. In classical political economy (see, for instance, Marx 1959), labour activities are, by definition, directed at the extra-somatic, external world. Not only do modern bioindustries produce a variety of "biologicals", agents extracted

from or generated by biological material, these biologicals perform their own labour. In order to draw attention to the significant economic role of women in the reproductive sector of biomedicine, Waldby and Cooper (2010) speak of "clinical labour". Expanding and rethinking existing concepts of labour, they recast the gift economy for reproductive material as a form of unacknowledged productive work. Rethinking the rhetoric of altruism often associated with assisted reproduction, Waldby and Cooper both draw upon and go beyond feminist analyses that have applied the logic of alienation to the context of the home and the family. For them, a major characteristic of contemporary relations of reproduction in biomedicine is "a denationalization of the reproductive sphere and its exposure to global precarious labour markets" (Waldby and Cooper 2010: 12; emphasis in the original).

Broadening the feminist perspective, we suggest that the labour carried out by both women and men contributing genomic stuff to biobanks, genomic projects, and personal genomics services largely goes unrecognized. Not only have the capacities of the body been fragmented and turned into instruments for production, redefining both human labour and human bodies, also the sites of labour and production have increasingly been separated as a result of complex and interrelated developments, including the growth of the World Wide Web, network society (Hardt and Negri 2000), and virtual migration (Aneesh 2006). "Paradoxically", Aneesh notes, "the new space of transnational labour has reversed its relationship with the worker's body. Rather than move the body across enormous distances, new mechanisms allow it to stay put while moving vast quantities of data at the speed of light" (2006: 2). Call centres of the kind studied by Aneesh underline the ability to perform work at a place other than the site of the acting body. In contrast to the "body shopping" represented by nannies and cleaners who physically move to the site where they are needed, the providers of genomic stuff are "virtual migrants", in Aneesh's sense (2006), at someone's service, contributing to transnational biobanks and databases that can be operated from anywhere anytime through the aid of the Internet and computing machinery. The "same" body, then, in a sense, performs labour at two or more sites simultaneously. These complex hybrids of the biomedical era pose complex questions for governance and property.

3. A kind of commons

As mentioned earlier, Ostrom sought to bring together strategies used by new institutionalists with strategies used by biologists for conducting empirical work (Ostrom 1990: 25). Biologists often try to reduce the complexity of their task by focusing their observations on simple organisms, in the hope that this may illuminate more general processes and the broader picture. Ostrom indicates that she follows a similar strategy:

My "organism" is a type of human situation. I call this situation a CPR situation. ... I focus entirely on small-scale CPRs, where the CPR is itself

located within one country and the number of individuals affected varies from 50 to 15,000 persons who are heavily dependent on the CPR for economic returns. These CPRs are primarily inshore fisheries, smaller grazing areas, groundwater basins, irrigation systems, and communal forests (1990: 26).

A quest to explore to what extent, and how, Ostrom's work on CPRs is applicable to genomic stuff must necessarily start with the question of what counts as the relevant "resource unit". The creation of property rights – and, by extension, the formation of regimes of governance – partly depends on the nature of the thing itself. As Rose has argued, property doctrine "often takes at least some of its shape from the material characteristics of the 'things' over which property rights are claimed. ... [T]he physical characteristics of the resource frame the kinds of actions that human beings can take toward a given resource, and these in turn frame the 'jural relations' that people construct about their mutual uses and forbearances with respect to the resource" (1994: 269). In what sense, then, does genomic stuff represent a "resource"? What, if any, are its material and physical characteristics, and what are their implications for appropriation and governance?

The material dimension signified by the term "genome" is contingent on the academic discipline, as well as the field of research and clinical practice; and it has changed over time (see Leonelli 2010). While the genome has long been seen as "an ensemble of genes strung along the chromosomes" (Barnes and Dupré 2008: 76), its materiality is different from that of the resources discusses by Ostrom. The genome is no materially bounded, discrete entity that can be mechanically separated from its environment, like fish, or water. It is a conceptual artifact signifying a system of meaning. The system in itself is complex, as (a) the definition of, and the relationships between individual elements, are not fully mapped out and (b) its boundaries are unstable (see Martin 2010). Keller's work is most instructive here: She argues that genes have been defined in either structural or functional terms, and that both of those dimensions are complex within themselves:

To the extent that we can still think of a gene as a unit of function, that gene (...) can no longer be taken to be identical with the unit of transmission, that is, with the entity responsible for (or at least associated with) intergenerational memory. Indeed, the functional gene may have no fixity at all: its existence is often both transitory and contingent, depending critically on the functional dynamics of the entire organism (Keller 2000: 70–71).

The question, as a result, of what counts as a "resource unit" in genomics is highly dependent on the context of its use. In patent law, for example, genomic stuff is treated in terms of chemical substances; the difference between material, data, and information can thereby be bypassed.⁵ A resource unit would thus be a certain set

⁵ For a discussion of the terminology of gene patenting, in particular of the conceptualization of the "genome" in distinction to the "gene", see Bostanci and Calvert 2008.

of chemical substances.⁶ In genetic association studies, in contrast, the resource unit is a particular unit of the DNA sequence. It could be a very small one – at the level of variations in single molecules (single nucleotide polymorphisms, SNP) – or it could comprise larger stretches of DNA which are present in multiples, or not present at all, in some individuals (this phenomenon is referred to as copy number variation, CNV). In genetic testing, a resource unit could be a unit of information (e.g. about the presence or absence of a mutation or variant in a specific gene which correlates with a disease), for example a particular allele, or – such as in the case of testing for Down's syndrome – an entire chromosome.

In sum, due to its ambiguous materiality, what the "resource" of genomic stuff is depends on the particular context and purpose of use. In virtually all of these uses, however, genomic stuff transcends national borders. As Thacker (2005: 18) emphasizes, the genome is "global in a technological sense: it is an online data-base, accessible all over the world". In its form as data, and as information, genomic stuff fits the definition of an international public good (IPG): "goods that transcend national boundaries and require mechanisms for global governance" (World Bank 2006; Pinto and Puppim de Oliveira 2008). Indeed, recent work on the global commons is relevant for thinking about the governance of genomic stuff as genomic data and information clearly constitutes an "endowment of global value, which may span the entire planet [...], or be located within national jurisdictions but with spillover properties with global externalities" (Pinto and Puppim de Oliveira 2008: 341). However, unlike many of the resources typically discussed under the umbrella of global commons – such as the climate, oceans, etc. – genomic stuff is not to be seen as a natural resource in every respect. While genomic material – the chemical substances that make up DNA – could be called natural, some valuable elements of genomic stuff, namely the descriptions, characterizations, and annotations of DNA in databases as well as the information derived from it, have a high social content, documenting context, history and ways of life.

Epigenetics draws upon the insight that "gene expression and subsequent phenotypic variance [is] not simply dependent on DNA sequence [...] but that its regulation appear[s] to involve [...] genomic neighbourhoods or genomic context" (Niewöhner 2010). Epigenetics thus highlights the importance of non-genetic factors within the body and other, non-somatic factors such as nutrition, life-style, environmental toxicants, smoking, etc.⁷ The lives of our parents and ancestors and the traditions and conditions of their communities in all their complexities – from dietary factors and exposure to toxic substances to behavioural habits – are

⁶ This can partly be explained by the genesis of gene patenting, which emerged from an analogy to the patentability of chemical inventions, which were described as substances and processes; see e.g. Eisenberg 2000; Bostanci and Calvert 2008.

⁷ Epigenetic information is not the only kind of information encoded in the genome which is not genetic. Other examples are micro RNAs (so-called mirs, or miRNAs), which also affect gene transcription.

embodied and memorized in our genomes, turning on some genes and silencing others, leaving a lasting and complex "hereditary" impact in a somewhat neo-Lamarckian fashion. To account for the growing awareness of non-genetic factors, new terms enter the field, such as epigenome, methylome, or interacteome. Thus, besides not having an evident (apparent and/or measurable) material expression, genomic stuff expands to incorporate ever-larger fields of non-genetic factors. This has important implications for governance.

4. Governing genomics: concrete cases

One of the contested issues in current discussions of genomic stuff is that of ownership and access. Biomedical knowledge and biovalue is increasingly produced within multinational companies that claim ownership of the stuff they use and the knowledge and technologies they produce. Obviously, this demands some kind of governance response at both the national and the global level. Which mode of governance would be appropriate for genomics? Ostrom's unique contribution to the question of how common property should be governed was to complicate debates on how to govern common-pool resources (CPRs) by showing that many common property regimes are governed reasonably well by their appropriators, and that the best governance models are often situated between the poles of either privatization or heavy governmental regulation (Aldrich 2010). This is how Ostrom (1990: 29) phrases her core research question: "How a group of principals – a community of citizens – can organize themselves to solve the problems of institutional supply, commitment, and monitoring is still a theoretical puzzle, [...g]iven that some individuals solve the puzzle, whereas others do not ...". Self-regulation on the side of appropriators of a CPR thus plays a particularly important role in Ostrom's work. Much recent work on the implications of biotechnology and gene patenting underlines the importance of addressing the relations of appropriators and the appropriated, raising classic questions of alienation and relations of production (Pálsson 2009). We argue here that stewardship and self-governance are typically also the most effective and efficient ways of governing genomics. In what follows, we discuss a few pertinent cases that reflect the wide variety of forms that the exploitation of genomic stuff can take (as well as its governance).

The history of the Human Genome Project (HGP) and the associated "Genome War" represents an important case, illuminating some of the strains in the moral economy of the new genetics (see Shreeve 2004). Funded by the US National Institute of Health and the Department of Energy, the project's aim was to "decode" the chemical units of DNA that make up the genetic pattern of humans and to openly share the results. The so-called GenBank became the main repository for publicly available genome data, regularly adding information in the process of sequencing, underlining the communitarian nature of the project. The plan of the non-profit government project, however, was soon challenged by a private enterprise, Celera Corporation, organized by Craig Venter. As was

to be expected, here was an intense tug-of-war between the two human genome projects, each side actively engaging in a tense public relations battle. These developments raised interesting questions about ownership which were actively contested in the academic community, the biotech industry, and the legal and political realms. In what sense did the human genome constitute a *common-pool* resource? Did it belong to humanity or was it up for enclosure by private interests and industry much like the high seas many years ago? What kind of governance would be appropriate?

One interesting case for the exploration of genomics in the aftermath of the HGP governance is that of the International Haplotype Map Project (in short, the "HapMap Project") that has focused on four populations with ancestry from parts of Africa, Asia, and Europe (HapMap 2005). The mapping of SNPs has been seen as a platform on which the understanding of what makes some people susceptible to common diseases will be built. The HapMap project is one of the spin-offs of the Human Genome Diversity Project (Cavalli-Sforza 2005), which, due to resistance of indigenous populations and disagreement about group consent requirements, suffered from difficulties in its implementation (Reardon 2005).

The data and information obtained through the HapMap project is made freely available in the public domain. The contentious issue, in the case of the project, was not related as much to the question of who owns the genetic information as it was about who the genetic information should be seen to represent: does it represent merely the group of individuals that it stems from, or the communities these individuals come from? If the latter should be the case, what are the boundaries of this community? While these questions have found pragmatic settlements for the purpose of the HapMap project, the question of representation in genomics continues to be pertinent (Ilkilic and Paul 2009). With its policy of making data freely available, however, the HapMap project has provided the basis for a wide range of research into disease susceptibilities worldwide.

Recently, genome researchers have repeatedly been painfully reminded that for some "native" groups the human genome is primarily a sacred phenomenon intimately connected to identity and belonging (on "native" culture, the Genographic Project, and similar projects, see, for example, Brown 2003; Pálsson 2008). To the extent that these groups describe the genome as a "resource", it is *cultural* capital, intangible property that is inseparable from the cultural meanings that it represents, that needs to be collectively guarded. Such a notion of cultural resources has sometimes developed in response to encroachment by biomedical industries, under threats of biopiracy and discrimination. A well-known case is that of the Havasupai tribe in the Grand Canyon who had provided DNA samples for researchers at Arizona State University since 1990 and later requested

⁸ In March 2000, US President Bill Clinton and Prime Minister of Great Britain Tony Blair issued a joint statement in an attempt to bring things under control, urging nations, scientists, and corporations to freely share their information on the human genome, emphasizing that the "book of life" belonged to every member of the human race.

(successfully) the return of their samples (Harmon 2010). For most genome researchers and common pool theorists, however, genomic stuff is by definition a resource, demanding specific rules of access and governance.

Large-scale sequencing studies, as we have seen, such as the HapMap project and the Human Genome Project have increasingly adopted rules of sharing and unrestricted data release (McGuire et al. 2008: 155); this has been seen to be essential keeping in mind that the primary purpose of the research is to establish a reference genome, a catalogue of genetic variation to which everyone would have free access when developing a variety of other research projects. One form of sharing that seems to be advancing is represented by "federated" databases that make it possible for those taking part in federation to access details from remote sources, rather than rely on a central "hub" with restricted access. Such databases "are a more complicated solution in terms of the required technologies, but they bring certain advantages that cannot be endowed by a centralized database" (Thorisson et al. 2009: 13). Federation, however, requires some level of selfregulation along the lines suggested by Ostrom. Legal provisions can provide highly useful frameworks, such as data protection laws, open source requirements, or disclosure requirements, without which the activity of such projects could be jeopardized and/or bearing significant risks for those participating in them. Positive legal norms cannot, however, accommodate the fluidity and contingencies of some of the core tenets of such projects: For example that the social, personal, and sometimes clinical meaning of genetic data and information can change; that stake holders' assessments of their own risks and benefits can change over time. and most importantly, that institutions can *learn*. As long as endeavours such as the HapMap project cannot coerce anybody's cooperation or monopolize access to data or knowledge that could otherwise benefit many, and as long as it depends on the voluntary participation of people, self-regulation is the most efficient tool for the governance of genomic stuff in this context.

The ontological ambiguity of the term genome, and genetic information, data, and material accounts for some part of the patchiness which characterizes deliberations about ownership and access to genetic stuff so far. Since the aforementioned "Genome War", a vast terrain has been opened up for formal and informal contracts between the key players in genome research, legal definitions of rights, patents, and prospecting and political debates on medicalization, democracy, and governance (Prainsack et al. 2008). One central issue for governance is that of exclusive licenses to gene patents. An interesting recent development on that score is the decision in March 2010 of a US federal judge to invalidate seven patents related to the genes BRCA1 and BRCA2, whose mutations have been associated with breast cancer. The judge argued that the patents, held by Myriad Genetics and the University of Utah Research Foundation, were "improperly granted" as they involved a "law of nature", falling outside of the realm of things that can be patented. If upheld, this decision will have far-reaching implications for biomedical research and the future of medicine. At present, more than 4000

sequences from human genes, covering about 20% of the human genome, are identified in at least one granted patent claim (Schwartz and Pollack 2010).

Another important development is represented by a large-scale empirical study by a team of scholars at Duke University (see Cook-Deegan and Heaney 2010). This study examined the benefits and harms that result from patenting and licensing practices in the field of genetic diagnostics, focusing on case studies involving ten clinical conditions, including breast cancer. Collectively, these studies show that gene patents, which have been issued since the 1980s, do more to stifle competition in the gene testing market than to facilitate the development of new technologies. This is, partly at least, a result of the complexity of the genetic interactions involved in the onset of the diseases involved, the fact that singlegene tests are giving way to multi-gene or even genome-wide scans (based on SNP analysis, but also employing full sequencing methods in a growing number of cases). These studies often seem to suggest the necessity, for the benefit of patients and health-care, of forms of governance alternative to those involving exclusive rights and private property. This is not, however, to suggest a strong form of genomic exceptionalism, of one kind of governance regime for all kinds of genomic contexts.

In 1998, two information and law scholars at the University of Michigan, Michael A. Heller and Rebecca S. Eisenberg, used the phrase "Tragedy of the Anticommons" to describe the situation within biomedical research where patents unduly limit access to resources: As a mirror image of commons property, in the context of anticommons property "multiple owners each have a right to exclude others from a scarce resource and no one has an effective privilege of use" (Heller and Eisenberg 1998: 698). We hold that in the context of genomic stuff, the value of this argument lays mainly in its power to support normative claims against the patentability of (representations of) naturally occurring entities within organisms. It presents a strong case for the negative unintended consequences of patenting as described above (Buchanan and Yoon 2000; Bovenberg 2004; Murray and Stern 2007), but it is not as helpful in thinking about governance regimes for genomics stuff more generally. Unlike microarrays (Park 2010) which are bounded materialtechnological entities that can contain elements patented by different parties, genomes are not rendered useless by multiple owners claiming patent rights to (representations of) parts of them. Patent protection for genes is only possible for isolated gene sequences and associated methods for its diagnosis or use; and also this has recently been challenged, as discussed earlier (see also Van Overwalle 2010). It is true that a patent on a gene sequence can limit the scope of actors who can carry out research pertaining to this sequence, and thus, develop diagnostic or even therapeutic applications based on it. However, it is questionable whether this has considerable implications for the realities of scientific practice, as it has been shown for Europe, for example, that the infringement of intellectual property rights does not seem to be a large concern for biomedical researchers in many labs (Gaisser et al. 2009). In addition, patenting of genomics stuff has already started

to be reconceptualised, as Van Overwalle (2010: 1631) suggested, "as a temporary permit to exploit monopoly rights under fair and reasonable conditions, investing technology owners with the authority to invent and share, in other words, as a 'duty bearing privilege'".

In some instances, research institutions utilizing a person's DNA are seen as custodians, stewards, or trustees (Winickoff and Winickoff 2003) of the genetic stuff, underling the language of "benefit-sharing" and "Common Heritage" of international law. Interestingly, as Hayden (2007: 751) points out, 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 collective bargaining". "Why", Hayden continues, "does bioscience, a site of newly intensified forms of privatization, provoke such a riot of collectivization?" One answer to this question may be that where immediate benefit for those who are asked to contribute to a project – such as a biobank – does regularly not materialize, and/or where governmental regulators play a strong role – such as in matters of public health, e.g. pandemics – communal benefit is sometimes the only value that can justify the measures undertaken. At the same time, pertaining to the fields of genetics and genomics specifically, references to collective values, benefits, or goods, are closely interlinked with a broader collectivist rhetoric, emphasizing that genes are something that humans have in common, something that makes us human and grants us equal rights (Prainsack and Naue 2006).

5. Stability of CPR regimes in genomics

Yet another question is whether the requirements that Ostrom (1990: 90–102) has defined for common property regimes to be stable arrangements can be implemented in the field of genomics in principle. Let us examine the eight principles one by one: (1) Clearly defined boundaries: "[actors] who have rights to withdraw resource units from the CPR must be clearly defined, as must the boundaries of the CPR itself' (Ostrom 1990: 91). With regard to the latter element, the boundaries of the CPR itself, we have argued above that genomic stuff is a bounded resource only in particular contexts of use. Furthermore, due to the fact that in contrast to Ostrom's appropriators, who always share connection to a common and bounded geographic area, the group of potential appropriators of genomic stuff is undetermined and they do not share a certain geographical area as a reference point, apart from - in some cases - those who have access to genomic material (e.g. blood from which DNA can be extracted; such access can be limited to researchers working for one university, for example). Access to, and exchange of, genomic data and information is largely transnational and takes place partly by virtual means. Once genomic data are in the public domain - as it is regularly required in the case of publicly funded research - nobody has either the right or the practical possibility to withdraw resource units from the

- CPR. However, as long as access to genomic data and/or information is limited to a certain scope of users (e.g. researchers eligible for free access to a genomic database), legal provisions and agreements usually determine parties which have the right to withdraw resource units from the CPR. Consequently, in some contexts, the "clear boundaries" requirement for CPR regimes to be stable can be satisfied in the context of genomic research.
- (2) Congruence between appropriation rules, local conditions, and provision rules: "Appropriation rules restricting time, place, technology, and/or quantity of resource units are related to local conditions and to provision rules requiring labour, materials, and/or money" (Ostrom 1990: 92). As Ostrom points out for the empirical cases that she observed, while there is no general rule to ensure that these rules are fair, "in all instances those who receive the highest proportion ... also pay the highest proportion of the fees" (Ostrom 1990: 92). In the case of genomics, governance regimes regulating access to genomic stuff are often asymmetrical in the sense that (a) those who already have access to large cohorts, in other words, who belong to a formal or informal group of researchers/ clinicians/users which has privileged or sole access to a resource, often carry lower costs for access than those who access the resource from outside; (b) actors in not-for-profit realms (e.g. genetic counsellors, researchers at public institutions, etc.) sometimes have the same degree of access to resources as actors in for-profit contexts but they pay lower fees for that access (Bastow and Leonelli 2010).
- (3) Collective-choice arrangements: "Most individuals affected by the operational rules can participate in modifying the operational rules" (Ostrom 1990: 93). Assessing the extent to which this is applicable to genomic resources depends on how we define the group of potential appropriators in the field of genomics. In Ostrom's work, an appropriator is somebody who utilises/processes the CPR to render it useful to a larger number of people and thereby creates profits for herself (e.g. the fisher who extracts fish from the sea and sells them at the market so that they can be eaten). The genetics researcher in our example is clearly a potential appropriator according to this definition. But who else could be seen as fulfilling the role of rendering the CPR useful to a larger group of people? What about the lay person who buys a genome test on the Internet? What about the clinician, or the genetic counsellor, who tests a patient for the carrier status for a particular genetic disease? Due to the difficulty of defining "genomic", the scope and group of potential appropriators is a priori undetermined. Whether all parties affected by operational rules can participate in modifying them can only be judged on a case-by-case basis.
- (4) Monitoring: "Monitors, who actively audit CPR conditions and appropriator behaviour, are accountable to the appropriators or are the appropriators" (Ostrom 1990: 94). Again, an assessment of the applicability of this condition to genomics is dependent on the particular context of use, and on how the scope of potential or actual appropriators is defined. In some instances,

those who monitor CPR conditions and appropriator behaviour are indeed the appropriators, such as in the case of patients receiving genetic counselling in a clinic; or even individuals who access genetic tests on the Internet. In their capacity as patients or consumers respectively, they can file complaints and report suspicions of malpractice to assigned authorities; in their capacity as citizens, they have some influence on regulation, although this influence is typically not immediate and in some cases nonexistent (e.g. when the company providing genetic testing services is located in another country and thus bound to legislation on which the consumer cannot have any influence). In other instances, such as a research consortium, whether appropriators can effectively audit and monitor the behaviour of other appropriators, and the CPR conditions in general, depends on the distribution of power within the network and can only be judged on a case-by-case basis. The latter also applies to Ostrom's fifth and sixth criteria for the durability and stability of CPR governance regimes, namely (5) graduated sanctions for appropriators who violate rules; and (6) low-threshold and low-cost conflict-resolution mechanisms.

- (7) Minimal recognition of rights to organize: "The rights of appropriators to devise their own institutions are not challenged by external governmental authorities" (Ostrom 1990: 101). The satisfaction of this requirement is relatively unproblematic. Various configurations of actors across the field of genomics, from data consortia to patient organizations to consumer groups, can "devises their own institutions" without being challenged by governmental authorities.
- (8) Nested enterprises: "Appropriation, provision, monitoring, enforcement, conflict resolution, and governance activities are organized in multiple layers of nested enterprises" (Ostrom 1990: 101). This requirement, as Ostrom specifies, applies only to larger, more complex CPRs. Again, it is not difficult to imagine that this requirement could be satisfied in the field of genomics. For example, databases for genetics research are often organized in multiple layers comprising different institutions, types of actors, and layers of governance structures.

Aldrich (2010: 270) summarizes the thrust of Ostrom's endeavour as follows: "the theoretical problem is the endogenous generation of an institution, where the institution, if successful, solves collective action problems inherent in achieving commitment to the use of the institution and monitoring of compliance to commitment". As argued above, the applicability of Ostrom's framework to the governance of genomics seems limited due to the fact that the boundaries of "genomics" are difficult to define and vary with institutional and disciplinary contexts; thus there is no "endogenous generation of an institution" that would be in a place to govern genomics as a CPR. On the other hand, as Boettke (2010: 283) points out about Ostrom's work, "[m]any of the effective tools for governance she found resided not in the formal structure of government, but instead in the informal, and sometimes even tacit, rules that communities live by".

The field of genomics consists of many communities that have established their own tacit, informal, and sometimes even more formal rules. Research collaborations – both formal and informal – revolving around sharing common databases could be an example. Access is sometimes dependent on an actor's formal and informal status in the community, whether she is known to be pleasant to collaborate with, whether she has a good cohort herself that renders her an interesting party to share resources with, etc. Thus, access depends on social, scientific, and institutional capital. In some instances it also depends on mundane factors such as an actor's geographical location, or the status of her organization, such as in cases where research funding is limited to members in a certain geographical area (e.g. the EU and associated countries) or database access is limited to not-for-profit research institutions. In genetic association studies, having access to large databases and cohorts increases one's chance to obtain meaningful findings and get published in top-notch journals. Big consortia often restrict access for smaller players, with the result that there is a tendency for bigger players to get bigger, and for smaller ones to become insignificant (Mayrhofer and Prainsack 2008).

The Public Population Project in Genomics (P3G) is an umbrella organization which helps those running or benefitting from biobanks to devise efficient modes of (self-)governance by facilitating the negotiation of voluntary codes of conduct, rules for exchange of data, etc. It could thereby be seen as a solidified configuration of mostly informal infrastructures and practices of governance and self-governance. Like the self-governing organization of appropriators in Ostrom's cases, members and associates of research databases, or also of P3G, devise access rules, monitor appropriator behaviour, penalise members who violate rules (mainly by cutting them off certain resources), etc.

6. To conclude

In the concluding pages of *Governing the commons*, Ostrom remarks that if the social sciences are to be relevant for discussions of policy problems "the challenge will be to integrate efforts to map the broad terrain and efforts to develop tractable models for particular niches in that terrain. Each CPR can be viewed as a niche in an empirical terrain" (1990: 214–215). Genomic stuff clearly represents an increasingly important empirical niche. In the modern age, a common wealth of genomic data, information, and material is rapidly being transformed into commercial property, much like distant lands and seas during the colonial era. No wonder that it has become the centre of debates on the relative merits of patenting and public trust, markets, and states – a CPR on its own. As we have seen, however, the issue of what constitutes genomic stuff, a central issue for the discussion of governance, is far from settled. Keeping in mind the (im)material complications of genomic stuff, we have suggested that Ostrom's thesis on self-regulated commons and stewardship is highly pertinent in this context. We do not, however, want to advance a strong form of genomic exceptionalism, implying

that genomic stuff as a CPR is different from other CPR in all respects. While developments in the real world of genomics – including the basis of genomics research, such as national biobanks, public databases such as the HapMap project, or legal trends relating to patenting, and the "Genome War" – point towards modes of self-regulation being the best – in the sense of the most feasible and most practicable – modes of governance, other developments in the field of genomics may point to other directions. This is a rapidly changing and expanding empirical, practical, and theoretical terrain with a variety of hybrid products each of which warrants an extensive study.

From the perspective of dominant gene talk, governance is limited to managing access to the stable hereditary material of the cell, to verticallyacquired genes and their assembly in particular individuals and populations and, more broadly, the human race. The Universal Declaration on the Human Genome and Human Rights underlines the common-property nature of the human genome, suggesting the genome "underlies the fundamental unity of all members of the human family ... In a symbolic sense, it is the heritage of humanity" (UNESCO 1997). Such a common-property perspective was partly the result of the Human Genome Project and the debates it generated. There are good grounds now for questioning such a narrow genealogical and gene-centered approach. For one thing, it turns out that the genomes of many organisms, including humans, are not static things neatly separated from other genomes. As Barnes and Dupré (2008: 136) note, "rather than thinking of ... genomes as the exclusive property of individual organisms, we should think of a metagenome encompassing all the genomic resources available to a microbial community". As a result, the genealogical view of life that emerged in Europe during the Middle Ages, a view that drew upon the metaphor of common "roots", is being replaced by rhizomic notions of relations, of decentered clusters of interlaced threads where everything is potentially interconnected with everything else. Helmreich (2009) suggests that while the empirical evidence available only minimally blurs the main picture it raises fundamental questions as to what should count as relatedness. Paradoxically, he points out, "the uprooting of the tree has followed ... from taking literally the notion that DNA contains information that can be employed to trace lineages" (p. 73).

Importantly, from the perspective of governance, organisms are partly regulated through a host of epigenetic, environmental forces that leave an "imprint" on their genomes, an imprint that may in part be passed on from one generation to another independent of the genetic code of DNA material. To what extent, then, does epigenetic knowledge break down the boundary between the body and the environment and what does this signify for governance (see Rothstein et al. 2009)? While many of the implications of epigenetics remain uncertain, it clearly presents important governance issues. Epigenetics offers a mechanism for the body to assess and react to the environment in which it is embedded. While the assessment and adjustment is sometimes harmful, the

mechanisms involved can possibly be averted through both drug development and deliberate governance measures designed for preserving the soundness of the environment.

Although the language of epigenetic research often seems to maintain the boundary between inside and outside rather than erase it, the empirical evidence seems to call for an approach to governance that avoids rigid analytical dualism. A meaningful post-genomic interpretation of the Universal Declaration on the Human Genome and Human rights, as a result, must expand the original text to underline the importance of the epigenome and the unity of body and environment. In order to govern genomes and epigenomes it is necessary to both manage access to certain parts of our environmental commons (clean air and water, in particular) and to *avoid* or minimize the impact of some others (toxic substances and radiation, for example).

Genomic resources are increasingly assembled and managed through the Internet and web-based networks. Thus, personal genomic services and biobanks engage people in the coproduction of biosocial networks involving DNA material and information about health and life style. Levina suggests, drawing upon her work on the commercial online genome testing service 23andMe, that "life in the network society requires of its denizens a constant contribution to the growth of the network. ... Members are encouraged to think of themselves as ... nodes, in the network" (2010: 2). If network subjectivity, she continues, is conceived in such terms "then each body—reduced to its information—can be abstracted from its social and cultural context. It becomes, in a sense, a free-floating signifier" (Levina 2010: 7).

Hardt and Negri emphasize the vital dimensions of biopolitics, focusing on the production and reproduction of life itself; for them, it would be misleading "to treat the new labouring practices in biopolitical society *only* in their intellectual and incorporeal aspects. The productivity of bodies and the value of affect ... are absolutely central in this context" (2000: 30). Perhaps it is necessary to react to the informatic, textual trend associated with the mapping of genomes and the "code of life". Indeed, life itself – in the form of stem cells, tissue, and organs – is a central component in the production of biovalue. Often, however, it is difficult to maintain a rigid distinction between the corporeal and the incorporeal. To resolve the ambiguity, we have suggested the notion of "genomic stuff". As long as one focused on the internal relations of cells and bodies, the issue of genomic governance seemed to resist the gaze and reasoning of political theory traditionally focused on the external "biological world". Now, however, it seems we are back in familiar terrain; genomic stuff invites standard questions about distributive issues, rights to meaningful participation, social justice, and intergenerational fairness. The spokespersons for the so-called Human Microbiome Project (Turnbaugh et al. 2007) anticipate the establishment of microbial observatories worldwide for the purpose of linking microbiomes to the planetary environment, and for facilitating sustainability. Life itself, its atomic structures and complex relations have entered the grand and seamless world of the Gaia.

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