

# Our social genome?

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**Apocalyptic views on the natural order, chimeras and genetic engineering should not detract from the fact that medical research, similar to the promotion of health, is a public good. Genomics crosses all species, thereby requiring a global approach that respects human rights and public health priorities. Public trust and public participation in research demand clear stewardship as well as transparent and accountable oversight. Characterizing fundamental genomic data as a public resource might counterbalance the current overemphasis on individual rights but this will not be simple. It is only through an attachment to justice and solidarity that the dignity and well-being of persons, both as humans and as citizens, can truly be fostered.**

## Introduction

[P]ast restraint ... [on] the technological transformation of our genetic constitution ... has traditionally been seen as dependant on maintaining a fundamental difference between the natural and the artificial – a difference placed in question by modern technology [1].

The completion of the mapping of the human genome has confirmed our close genetic proximity to the mouse, the worm and to each other. Therefore, are humans just another form of living matter, a biological resource for the ever-expanding markets of biotechnology? Furthermore, will the biological be replaced by cyborgs and prosthetics, that is, by the mechanical post-human?

Any response to these questions requires some understanding of actual and potential scientific 'advances'. At the level of the species as well as the level of the individual, humans have co-evolved and co-adapted with nature. Moreover, each person is more than the sum of their biological or prosthetic components. As such, should there be socio-ethical and legal frameworks that protect and promote the human person as a member of humanity? To answer this question, we must first examine three current social representations found in the debate on the post-human: the natural order; species integrity; and the individuated self. We will argue first that these representations are inadequate because they are premised on a static view of nature. Second, we will argue that the social reconstruction of humanity, and so of the person, could be fostered through the concept of the common good, relying on the notions of common heritage, global public goods and open science. In short, the issue before us is what are or could be our biological and social geographies? Our

collective reply might well determine not only the future of the social contract but also the possibility of achieving global justice.

## The scientific invention of the post-human

### *The natural order*

The scientific invention of the post-human is considered as contrary to the natural order. It could be argued that in popular culture, in spite of our Pasteurian knowledge about bacteria and of the life-saving power of blood transfusions, the modern Promethean image of the regenerative and/or replicable self began with the first heart transplant by Christian Barnard in 1974. Because the heart is seen as the locus of the soul, any interference with the natural order is equated with 'playing God'. Under this school of thought, the natural self holds the body as sacred in contrast to the non-human. Today, the essential human being is understood as a necessary reference point for the continuation of human experience and the construction of an ethical community [2]. However, the line between the human as a product of nature and that of the human as a fabricator of nature is becoming blurred, with the human as a fabrication of technology. Can we bear the moral burden of responsibility for the creation of a 'second nature' to our own?

Under the natural order, infertility treatment interferes with the will of God, the notion of linearity in genealogy and the genetic lottery. Permitting parental choices that include the timing of offspring, their origin, their number and their quality is 'unnatural'. Human nature is understood as pre-determined and static. Under the natural order, genetic engineering is antithetical to predetermined diversity. Paradoxically, if taken to the extreme, we maintain that this position leaves the human person even closer to plant and animal species and the vagaries of natural selection and survival. However, it is supported by both the religious right and the eco-environmentalist left [3]. Surely, we can make intelligent choices with regard to nature that are based on a human conception of what is natural, not on a naturalistic definition of what is human.

### *Species integrity*

The argument for the preservation of species integrity is to some degree a logical extension of the above approach. In spite of having bred animals and hybridized plants for centuries, new possibilities such as xeno-transplants and the creation of chimeras are perceived as an affront to the hierarchical superiority and separateness of the human species [4]. In the past two decades, however, mice models have been created and used for the testing of human diseases. Through recombinant research, genes can be

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spliced together from different species that would never be able to mate under normal non-laboratory circumstances. There might be an intuitive repugnance to the specter of genetically manipulated pig hearts or kidneys being placed in humans. However, if safety is proven, familiarity and comfort with classical species categories is, in itself, insufficient to justify valuing and retaining such categories in the face of human suffering.

Human dignity is at the core of species integrity concerns. What components or capabilities are so closely associated with human dignity that the development of human–nonhuman chimeras would violate it? Human dignity is inherent in the human person as a person. Is a person with a pig heart valve less of a person? What is inherently human is inalterable and inalienable.

### *Individuated self*

The most solidly anchored of all notions of humanness is that of the concept of the individuated self, the last bastion against the post-human subject, today seen as a collection of interchangeable components. If science can produce cyborgs and clones, what is distinctively individual? Under this approach, the deliberate, external engineering of life is seen as endangering the conscious, sentient mastery of the planet [5].

Biology contains information – both material and immaterial – that is transformed by technology. Ten years ago, the fear was of the geneticization of society [6], whereas now it is the fear of the re-design of life: the realization of the proverbial *Homo superior* [7]. The issue here is the capacity, through nanotechnologies or self-sourced human stem cells, to replace, slow down or impede defective or ailing body parts or functions. Like Prometheus, the regenerative and regenerated self is chained to the rock of scientific progress, which does not permit us to die. (Or perhaps, the goal of regenerative medicine is to die healthy?). Will we, however, become personally responsible for not preventing, avoiding or replacing our run-down body parts? Indeed, new forms of intervention to improve quality of life might well increase individual choice but also impose onerous responsibilities for the exercise (or not) of such choices.

Power, as Foucault has argued, is now exercised at the level of life – as a form of biopower [8]. This enables individual control – in the name of individual claims to a ‘right’ to life – of health, of the body of an individual and to the satisfaction of the needs of an individual. The current choices offered by preimplantation diagnosis of embryos are a case in point.

Are the results of preimplantation choices different from germline modification, which is currently prohibited? Germline modification would affect the reproductive cells, whereby deleterious genes are not passed on to the next generation. However, preimplantation choices also prevent the transmission of recessive genes to the next generation. Ironically, at the same time, treatment of other conditions, such as diabetes, enables the transmission of genes that a century ago would have been selected out because afflicted persons would die before reproducing.

The rhetoric of choice clearly resonates with the ethics of autonomy. Respect for autonomy was largely developed in

the research domain following the atrocities of World War II [9], and in the clinical realm with the debate regarding brain death, euthanasia and the persistent vegetative state, in the 1970s [10]. It has spawned laws and ethics frameworks in which the individual and individual choice reigns supreme. Although fears of designer babies have not materialized, the genomic and post-human management of the person, and in turn that of the population, might erase individual embodiment: the possession of the body by its own being.

According to Rabinow and Rose:

[t]he stakes here are high, economically, medically and ethically. They lie in the presumed capacity of genomics to form a new ‘know how’ that will enable medicine to transform its basic logic from one based upon restoring the organic normativity lost in illness to one engaged in the molecular engineering of life itself [11].

But the fear of slipping as a reason to halt genetic engineering is equivalent to denying afflicted individuals therapy on the grounds that humans cannot make distinctions, as moral agents, between the remedial and the eugenic. The problem might well be the locus of choice; it is perhaps the collective ‘we’ that, in the name of individual rights, have not had the courage to make the difficult choices.

In short, the prevailing ethos admires and supports the intellectual curiosity of each individual to improve the frontiers and content of human nature. The individuated human self is protected through both laws and ethics. It could be argued that contemporary clinical ethics, research ethics and legislation favoring autonomy at all costs have indirectly favored the scientific invention of the post-human. To establish a degree of social control of genetic engineering, it will first be necessary to acknowledge that the principle of respect for individual autonomy is not absolute. Indeed, we need to re-ground our humanity in our sociality; we might need to socially reconstruct humanity to protect the person as human.

### **The social reconstruction of humanity**

It was argued, 15 years ago, that genome mapping would enable us to demonstrate not only genetic diversity and individuality within a given biological family but also common kinship: the interrelatedness of humans on this highly individualized but common map [12]. The Human Genome Project could thus be seen as a step towards the recognition of the human family, leading to the realization that ‘[t]he social geography of the human genome is both collective and individual’ [12]. However, in 2003, the World Health Organization (WHO) in a report titled *Genetic Databases: Assessing the Benefits and Impact on Human and Patient Rights* stated that:

We have, then, a fundamental tension between the possibility of considerable public good on the one hand, and the potential for significant individual and familial harm on the other. The basic interests that lie in the balance are those between human dignity and human rights as against public health,

scientific progress and commercial interests in a free market [13].

This is a false dichotomy. Human dignity and human rights need not necessarily be set up against public health, scientific progress and commercial interests in a free market.

Our attempt to socially reconstruct humanity begins with the recognition that 'the universal basis of our common genetic heritage may serve to ensure the appreciation of its international nature and the avoidance of individualistic, property concepts' [12]. Next, we will examine the concept of global public goods. Finally, we will conclude with an appeal for a return toward the humanistic ideal of open science. Through the application of these different ethical and legal concepts, one reality emerges: the genome is a global resource, the future development of which is of interest to humanity as whole.

#### Common heritage

The evolving legal notion of the common heritage of humankind draws its origins from the philosophy of Hugo Grotius and the Roman legal concepts of *res communis* (something owned in common by the community) and *res extra commercium* (things common to all, categorized as outside commerce) [14]. It is meant to regulate the use of areas and resources belonging to the terrestrial (e.g. oceans), celestial (e.g. outer space) or incorporeal (e.g. human rights) domains that are of interest to all of humanity. The essential elements of the common heritage of humanity are: (i) use must be for purposes consonant with peace; (ii) access must be open to those who have a right to it, while the rights of others must be respected; and (iii) sharing must be equal. This international concept stems from the need to prevent ownership of things of communal interest and to preserve things that are of international significance for future generations [12]. It has been proposed by several developing countries that a notion of the common heritage of humankind should constitute a principle similar to the *jus cogens* (peremptory norm) principle in international law. Such recognition would imply that this concept is imperative and does not permit derogation by states, persons or international organizations [14].

The essential elements of the common heritage could apply to the human genome at the level of the species. This notion would not restrict nor forbid biotechnology patenting. Rather, it would protect the genome from harm at the level of the species, such as preventing the loss of genetic diversity or the propagation of harmful (human-induced) mutations. It would also give rise to an active duty-of-stewardship, justified by the international interest in the important public health repercussions promised by genomic research.

The concept of the common heritage of humankind was integrated into Article 1 of the 1997 Universal Declaration on the Human Genome and Human Rights by the International Bioethics Committee of UNESCO [15]. Political misunderstanding and wrangling, however, led to the adoption of a text that reduced the concept to a symbolic one and to the removal of the word 'common'. The final version now reads:

The human genome underlines the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.

Nevertheless, the common heritage of humanity remains the bedrock of ethics for several of the major organizations interested in the advancement of health-related human genetic research, such as the Human Genome Organization (HUGO; <http://www.hugo-international.org/>) [16] and the WHO. International law is constantly evolving, and the repeated association of the concept of the common heritage of humanity with the human genome could, with the support of the international community, eventually lead to the creation of a new rule of international law.

#### Global public goods

Another concept from international law that has recently re-emerged is that of global public goods. Originally developed by David Hume and Adam Smith in the 18th century, this concept lately came back to the fore in the much publicized debate on global public justice in access to AIDS drugs by developing countries [17]. To be considered a global public good, the benefits of a public good have to be enjoyed by all (non-excludable) and consumption by an individual should not deplete the good nor restrict its consumption by others (non-rivalrous). Furthermore, the benefits of a global public good should be quasi-universal in terms of countries, people and generations [18]. Genomic knowledge probably qualifies as a global public good [19].

The concept of global public goods has been instrumental in shaping the building and use of genomic databases. The 2002 HUGO Statement on Human Genomic Databases held population genomic databases, and the primary sequence data held therein, to be global public goods. According to this organization, these goods should be enjoyed by all, without detriment to others. The recommendation reads as follows:

1. Human genomic databases are global public goods. (a) Knowledge useful to human health belongs to humanity. (b) Human genomic databases are a public resource. (c) All humans should share in and have access to the benefits of databases [20].

'The language of global public goods is a strategic concept in arguing for international collaboration in genomic research, and for global benefit-sharing of its results' [21]. It is crucial for harnessing genomic knowledge in a way that it can contribute to health equity, particularly among developing nations.

#### Open science

Underpinning this renewed interest in models of public values and the common good as a way of protecting and promoting the individual, first and foremost, as a citizen is the ideal of open science. It could be argued that, today, this humanistic approach to science has been replaced by an economic one, where academic research has become increasingly commercial and subjected to the realities of intellectual property. Nevertheless, scientific progress remains associated with an ideal of free and open dissemination of scientific knowledge [22].

It has been suggested that under this open science ideal, there is a norm of common ownership of academic research results. According to this norm, scientific findings are a product of social collaboration, a common heritage that should be dedicated to the scientific community [23]. In light of this value of communality, 'claiming property rights in inventions or keeping discoveries secret [is] perceived as immoral' [24]. Although, the past existence of such a norm within the scientific community is subject to debate [25], the norm of 'communalism' viewed as a social and humanitarian ideal is certainly appealing to the scientific community.

Following the advent of what has been called the 'networked information economy', important goods that are valued by human beings can now be produced by individuals, who interact with each other socially as human beings and as social beings, rather than as 'market actors' through the price system [26]. This transformation in the means of production now offers the scientific community the tools to make the ideal of open science a reality. In the field of genetics, this new 'networked information economy' has permitted social solidarity to manifest itself in the form of open models of collaboration, generating successes with both the SNP Consortium (<http://snp.cshl.org/>) and the International HapMap Project (<http://www.hapmap.org/index.html.en>).

The SNP Consortium was an initiative combining academia, foundations and pharmaceutical companies from five countries, in a race to make the results of the genome sequence mapping effort available to all, in an open and publicly accessible database. The success of this pre-emptive, pre-competitive effort was such that the International HapMap Project, a resource to assist researchers in finding genes associated with human disease and responses to pharmaceuticals, which was completed in 2005, favored a similar approach. In the end, because the haplotype blocks have remained largely intact, providing an unbroken thread that connects all people to a common past and to each other, the results of the HapMap Project underscored the fundamental, biological unity of the human 'family' across different races [27,28].

The private sector is also beginning to recognize the powerful potential of collaboration, both at the international and national levels. In 2001, several major pharmaceutical companies created a CEO Roundtable on Cancer (<http://www.ceoroundtableoncancer.org/>) to break down the walls dividing the drug makers of the world for an all-out effort against cancer [29]. The roundtable is considering a research plan to spread both the risks and rewards of drug discovery across a wide pool of companies (<http://www.ceoroundtableoncancer.org/>). The legal obstacles, such as intellectual property rights and antitrust legislation, are formidable but this new type of development model could offer the right combination of incentives to appeal to a growing number of industry players.

What then are the implications of this common good approach for biotechnology? We argue that a new global regime is required in the health sector, to respect human rights and public health priorities. Both public access and private innovation are needed to stimulate R&D with equitable outcomes. A global framework on essential

health research and development is being proposed [30]; likewise, there is a move in academia to promote equal access to university research [31]. Funding agencies, although aware of commercial necessities, are also becoming more sensitive to the importance of sharing resources and results for the benefit of the scientific community and humankind as a whole [32,33].

## Conclusion

In conclusion, we have argued that humans hold a special place in nature. Even so, apocalyptic views on biocolonialism, the order of nature, chimeras and genetic engineering should not detract from the fact that medical research, similar to good health, is a public good. All of us, as individuals and as members of families and of society, have benefited from the altruism of those who participated in research in the past [34].

We must seek 'the elusive balance between respecting the dignity of human persons and generating public goods (ultimately promoting the dignity of the human species), a balance that has been unsettled by the new modalities of biological science technology and property' [35]. The greatest threat to humanity is both the absence of recognition of science and of the human family. We are all the children of the *Homo sapiens sapiens* that came out of Africa 100 000 years ago, even although we do not speak the same language, have the same culture or religion and do not look alike.

It is only through an attachment to justice and solidarity (exemplified in the spirit of cooperation in our biological and social geographies) that the dignity and well-being of persons, both as individuals and as world citizens, can be ensured. We cannot scientifically invent the human, but we can foster the common good so as to promote the humanity of each person.

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## References

- 1 Baillie, H.W. and Casey, T.K., eds (2005) *Is Human Nature Obsolete?*, MIT Press
- 2 Fukuyama, F. (2003) *Our Post-Human Future: Consequences of The Biotechnology Revolution*, Piccador
- 3 Silver, L. (2006) *Challenging Nature: The Clash of Science and Spirituality at the New Frontiers of Life*, Harper and Collins
- 4 Karpowicz, P. et al. (2005) Developing human–nonhuman chimeras in human stem cell research: ethical issues and boundaries. *Kennedy Inst. of Ethics J.* 15, 107–134
- 5 Corbett, J.M. (1998) Reconstructing human-centred technology: lessons from the Hollywood dream factory. *AI. & Soc.* 12, 214–230
- 6 Lippman, A. (1991) Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *Am. J. Law Med.* 17, 15–50
- 7 Knoppers, B.M. (2006) The globalized gene. *CMAJ* 174, 355–356
- 8 Foucault, M. (1998) *The History of Sexuality: Will to Knowledge* (Vol. 1), Penguin Books
- 9 U.S. Government (1949) Nuremberg Code. In *Trials of War Criminals Before the Nuremberg Military Tribunals Under Control Council Law No. 10* (Vol. 2), US Government Printing Office
- 10 Jennett, B. (2002) *The Vegetative State: Medical Facts, Ethical and Legal Dilemmas*, Cambridge University Press

- 11 Rabinow, P. and Rose, N. (2006) Biopower today. *Biosocieties* 1, 195–217
- 12 Knoppers, B.M. and Laberge, C. (1991) The social geography of human genome mapping. In *Genetics, Ethics and Human Values: Human Genome Mapping, Genetic Screening and Therapy* (Bankowski, Z. and Capron, A., eds), pp. 30–35, Council for International Organizations of Medical Sciences
- 13 World Health Organization (2003) *Genetic Databases: Assessing the Benefits and Impact on Human and Patient Rights*, World Health Organization
- 14 Sucharitkul, S. (1989) Evolution continue d'une notion nouvelle: le patrimoine commun de l'humanité. In *International Law at a Time of Perplexity: Essays in Honour of Shabtai Rosenne* (Dinstein, Y. and Tabory, M., eds), pp. 887–908, Martinus Nijhoff
- 15 United Nations (1999) Universal Declaration on the Human Genome and Human Rights, G.A. res. 152, U.N. GAOR, 53rd Sess., 11 November 2003, United Nations, ([http://portal.unesco.org/en/ev.php-URL\\_ID=13177&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html))
- 16 The Human Genome Organisation (1999) Statement on cloning. *Eubios J Asian Int. Bioethics* 9, 70–72
- 17 Morrissey, O. et al. (2002) Defining international public goods: conceptual issues. In *Strategies For International Public Good* (Ferroni, M. and Mody, A., eds), pp. 31–46, Kluwer Press
- 18 Kaul, I. et al. (1999) Defining global public goods. In *Global Public Goods – International Cooperation in the 21 Century* (Kaul, I., Grunberg, I. and Stern, M.A., eds), pp. 2–20, Oxford Press
- 19 Thorsteinsdóttir, H. et al. (2003) Do patents encourage or inhibit genomics as a global public good? In *Populations and Genetics: Legal and Socio-Ethical Perspectives* (Knoppers, B.M., ed.), pp. 487–504, Martinus Nijhoff
- 20 HUGO Ethics Committee (2004) Statement on human genomic databases, December 2002, HUGO ([http://www.hugo-international.org/Statement\\_on\\_Human\\_Genomic\\_Databases.htm](http://www.hugo-international.org/Statement_on_Human_Genomic_Databases.htm))
- 21 Chadwick, R. and Wilson, S. (2004) Genomic databases as global public goods? *Res. Publica.* 10, 123–134
- 22 Joly, Y. Open sources approaches in biotechnology: utopia revisited. *Maine L. Rev* (in press)
- 23 Eisenberg, R.S. (1987) Proprietary rights and the norms of science. *Yale L. J.* 97, 177–231
- 24 Rai, A.K. (1999) Regulating scientific research: intellectual property rights and the norms of science. *NW. U. L. Rev.* 94, 77–152
- 25 Kieff, F.S. (2000) Facilitating scientific research: intellectual property rights and the norms of science – a response to Rai and Eisenberg. *NW. U. L. Rev.* 95, 691–705
- 26 Benkler, Y. (2006) *The Wealth of Networks: How Social Production Transforms Markets and Freedom*, Yale University Press
- 27 Gibbs, R.A. et al. (2003) The international HapMap project. *Nature* 426, 789–796
- 28 NIH News Advisory (2002), International consortium launches genetic variation mapping project. HapMap Will Help Identify Genetic Contributions to Common Diseases, October 2002 (<http://www.genome.gov/10005336>)
- 29 Warner, S. (2003) Collaboration against cancer. *The Scientist* 17, 48
- 30 World Health Organization (2006) *Global Framework on Essential Health Research and Development*, World Health Organisation ([http://www.who.int/gb/ebwha/pdf\\_files/EB117/B117\\_R13-en.pdf](http://www.who.int/gb/ebwha/pdf_files/EB117/B117_R13-en.pdf))
- 31 Universities Allied for Essential Medicines (2006) *Philadelphia Consensus Statement*, (<http://www.essentialmedicine.org/cs/wp-content/uploads/2006/10/philadelphiaconsensusstatement.pdf>)
- 32 The Wellcome Trust (2003) *Sharing Data From Large-Scale Biological Research Projects: A System of Tripartite Responsibility*, The Wellcome Trust (<http://www.wellcome.ac.uk/assets/wtd003207.pdf>)
- 33 National Institutes of Health Office of Extramural Research (2003) NIH Data Sharing Policy, National Institutes of Health ([http://grants.nih.gov/grants/policy/data\\_sharing/](http://grants.nih.gov/grants/policy/data_sharing/))
- 34 Harris, J. (2005) Scientific research is a moral duty. *J. Med. Ethics* 31, 242–248
- 35 Winickoff, D. and Neuwann, L. (2005) Towards a social contract for genomics: property and the public in the 'biotrust' model. *Genom. Soc. Pol.* 1, 8–21

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