

Bioethics and Genomics

George J. Annas*

Genomics, the study of an individual's entire genome, is often viewed as a potential medical saviour not just through "personalized" medicine in the developed world,¹ but also through application of genomic technology in the resource-poor world.² There is extensive literature on the bioethical issues involving genomics in both Europe and the United States (US), and bioethics has been used to frame the relationship between "Genomics and World Health" by the World Health Organization (WHO) as well.³ Although the WHO has adopted a health and human rights perspective, in their 241 page report on genomics and world health, human rights are mentioned only once, and then in the context of genetic enhancements, that is, using genetic manipulations to try to make "better babies" or simply better humans:

"Societies have a moral obligation grounded in equity or justice and human rights to ensure access to health care for their citizens. A fundamental part of the moral imperative of health care is its role in maintaining normal function, and in turn helping to secure equality of opportunity for persons that serious disease and disability undermine. Genetic enhancements of normal function, on the other hand, do not serve justice in this way and if and when they become possible, will almost certainly not be regarded as part of the social obligation to provide health care to all members of society."⁴

Put another way, the Advisory Committee on Health Research (ACHR) concludes that only some members of society, the elites, need have a right to

the new genetics, and physicians who care for this elite can do so without worrying about medical ethics. Whether one finds appeals to the “norm” of humanity or species function persuasive as lines that circumscribe the “right to health” or not, genetic technologies will certainly change the way we think about ourselves and our species, and thus how we think about the right to health, including access to health care, and bioethics. This chapter aims to explain why genetics and bioethics seem to be naturally paired in global health, and why, nonetheless, a human rights framework – which focused more directly on equality including its mirror, non-discrimination, and the right to health itself – could prove more useful to meeting the basic goals of social justice.

Bioethics, most often referred to simply as medical ethics, deals primarily with decisions made in the doctor-patient relationship, and secondarily with the researcher-subject relationship. It is in this latter context that bioethics and genomics have been most widely discussed. The risks of genomic research, for example, are the subject of chapter six (‘Potential risks and hazards of the applications of genomics and their control’) of the Report of the WHO’s ACHR. The chapter highlights three areas that present special risks: Germline genetic alterations; the establishment of genetic databases; and the application of genomics to biowarfare. The authors conclude that it is premature and dangerous to attempt germline genetic alterations; that nothing can stop the establishment of population-based gene banks (but that rules to protect privacy and guard against discrimination are required); and that the scientific community should take the risk of biowarfare applications of the new genomics seriously. The WHO report concludes on mixed notes of hope and caution: The “new and rapidly evolving” field of genomics “offers considerable possibilities for the improvement of human health” but “the full extent of its possible hazards are not yet fully appreciated.”⁵

A Canadian group followed up the WHO report with an exercise designed to identify the new biotechnologies most likely to be helpful to improving the health of people living in developing countries. Their report, based on expert assessment using a Delphi methodology, put two genomic-based technologies at the top of their final list, and a related technology third. First, modified molecular technologies for affordable, simple diagnosis for infectious diseases; second, recombinant technologies to develop vaccines against infectious diseases; and third, technologies for more efficient drug and vaccine delivery systems.⁶ The thesis of the Canadian report

is that “biotechnology can help to bridge rather than deepen existing divides between the developed and developing world.”⁷ On the other hand, the authors recognize that there is no technological fix for health, and that we will require a balanced approach: “Biotechnology will never be a panacea to current health inequities, but the evidence demonstrates that it is rightly considered part of the solution.”⁸ On this subject, WHO’s ACHR arrived at a similar conclusion: “None of these advances will be of any value unless the developing countries can evolve the health care systems on which these new advances can be based.”⁹

All this is still pretty vague. Of course we all hope that the new genomics will help bridge the gap between the rich and the poor, and the developed world and the underdeveloped world, as it improves the lives and health of those it touches directly. But none of this will be automatic, and WHO’s ACHR was right to highlight the dark side of genomics to health and development. The ACHR could have gone much further in this regard, and would have, had they employed a human rights framework instead of the more limited bioethics framework in their analysis. Here is how (I think) it should be done in the contexts of equality and the right to health.

Equality, genomics, and the risk of genism

Equality based on human dignity is at the core of a human rights approach to health. For example, a country’s obligation to “respect” and “protect” the right to health requires governments to “refrain from denying or limiting equal access to all persons” and to “ensuring equal access to health care ...” The new genetics can be seen as scientific validation of human equality in that it demonstrates that we all share substantially identical genomes; but it can also be used to foster prejudice and discrimination, and thus to undercut the right to health. This human tendency to create divisions, which at least some people would describe as genetic, is well illustrated by an incident in late 2007 when the co-discoverer of the structure of DNA, James Watson, scandalized the world when he ignorantly told a British newspaper, “I’m inherently gloomy about the prospect of Africa because all our social policies are based on the fact that their intelligence is the same as ours, whereas all the testing says not really.”¹⁰

Watson later apologized and acknowledged that there is no scientific evidence to support his statement about differences in intelligence among races. *Nature* magazine editorialized that Watson’s remarks were

“rightly ... deemed beyond the pale”, but also warned: “There will be important debates in the future as we gain a fuller understanding of the influence of genetics on human attributes and behaviour. Crass comments by Nobel laureates undermine our very ability to debate such issues, and thus damage science itself.”¹¹

Our superficial perceptions of each other have often fostered racism in the past. Simply defined, racism is “the theory that distinctive human characteristics and abilities are determined by race.” The hunt for genes, especially in groups identified by racial classifications, could lead to “genism” (a term not yet officially recognized, but one which could be defined as “the theory that distinctive human characteristics and abilities are determined by genes”) based on DNA sequence characteristics with resulting discrimination as pernicious as racism. Watson’s ignorant remark was not one of an old-time racist, but of a new-style “genist”.

The great hope of human genomics has been that it will scientifically demonstrate that humans are all essentially the same, and that this demonstration will inhibit our penchant for making arbitrary distinctions among humans. And genomics has already accomplished the science part. After the draft of the human genome was announced in 2000, for example, Chris Stringer of London’s Natural History Museum observed: “We are all Africans under the skin.”¹² The same point was made by other geneticists in different words, one noting that “race is only skin deep”¹³ and another, that “there is nothing scientific about race: No genes of any sort pattern along racial lines.”¹⁴ Craig Venter, the leader of the private genome mapping effort, concluded: “Race is a social concept, not a scientific one. We all evolved in the last 100 000 years from the same small number of tribes that migrated out of Africa and colonized the world.”¹⁵

This is all to the good, and geneticists deserve high praise for getting this antiracism message out to the public early. Unfortunately, the message of genetics, while undercutting racism, can simultaneously invigorate its evil brother, genism. This is how it works. Eric Lander, the genomics leader from the Massachusetts Institute of Technology noted in 2000 that, although we are all 99.9% genetically identical, that 0.1% of difference is made up of three million spelling variations in our genomes.¹⁶ Each of these genetic variations could be used as a pseudoscientific basis for discrimination based on genetic endowment.

Genome leaders have recognized this, and have called for legislation to prohibit genetic discrimination in employment, health insurance, life

insurance, and disability insurance. This is reasonable, but genetic discrimination can only happen if private genetic information is shared – and to protect genetic privacy, we must not only ban genetic discrimination, but also regulate the collection of DNA samples, their analysis, and their storage. There is some irony in the fact that James Watson's genome is one of the few that has been sequenced. After his offensive remarks, an analysis of Watson's own genome was published that disclosed that he has, according to Dr. Kari Stefansson of DeCode Genetics, 16 times the number of genes considered to be of African origin than the average white European, or about the same amount of African DNA that would show up if one great-grandparent were African.¹⁷ This does not, except to a genist, mean that Watson is African – but it should help demonstrate that genes alone tell us very little about the social construct we call race, and little about full-bodied humans.

The WHO's ACHR was right to worry about the proliferation of "DNA banks" and the lack of agreement on how to protect the genetic privacy of those whose DNA is stored and analysed in this context. An especially disturbing example of a human rights violation spurred by genomics is provided by the, now defunct, Human Genome Diversity Project, which sought to collect DNA samples from some 700 of the world's isolated ethnic groups, sometimes referred to as the world's "vanishing tribes". In the project's view, it was more important that science seize the opportunity to collect DNA from these peoples than that any action be taken to actually help the peoples themselves. The indigenous peoples around the world properly and forcefully rejected this project, and insisted that their human rights be placed above this dubious and reductionistic project.¹⁸ Nonetheless, this project has re-emerged in another guise under the rubric of the National Geographic Project and the sponsorship of the *National Geographic*.¹⁹

It is true that "we are all Africans under the skin." It is also true, nonetheless, that if we decide to search for genetic differences in the 0.5% of our DNA that is different, we will find them and use them against each other. Philosopher Eric Juengst put it well: "No matter how great the potential of population genomics to show our interconnections, if it begins by describing our differences it will inevitably produce scientific wedges to hammer into the social cracks that already divide us."²⁰

Preventing genism from taking over where racism left off, by substituting molecular differences for skin colour differences, will not be easy. Two actions, however, seem necessary. First, genetic privacy must be protected.

To help protect an individual's bodily integrity and security, no-one's genes should be analysed without express authorization, and, of course, no "genetic identity cards" should be permitted. Second, to help protect equality and the principle of non-discrimination, pseudoscientific projects that purport to identify genetic differences between "races" should be rejected.

The prospect of genetic genocide

The WHO's ACHR may seem to have spent too much time and emphasis on addressing the use of genetics to "enhance" human beings, specifically by making changes at the embryo level that could produce "better babies". But they were right to highlight this area, and that, although the technique is not currently possible, it is a subject that deserves far wider attention, especially in the human rights community. James Watson, this time from statements he made at a 1998 conference on Engineering the Human Germline, again provides an introduction to our discussion:

"It seems to me the question we are going to have to face is, what is going to be the least unpleasant? Using abortion to get rid of nasty genes from families? Or developing germline procedures with which ... You can go in and get rid of a bad gene ... And the other thing, because no one has the guts to say it, if we could make better human beings by knowing how to add genes, why shouldn't we do it? What would be wrong with it? ... if you could cure what I feel is a very serious disease – stupidity – it would be a great thing for people who are otherwise going to be born seriously disadvantaged."²¹

Screening genomes to detect differences creates more opportunities for discrimination. Using the new genetics to try to make a "better human" by genetic engineering goes beyond discrimination to elimination by raising the prospect of genetic genocide. This inflammatory language is justified. The project to make a better baby by genetic engineering begins with attempts to "cure" or "prevent" genetic diseases, but will almost inevitably lead to attempts to "improve" or "enhance" genetic characteristics to create the superhuman or posthuman. It is this project that, if successful (a large scientific "if") creates the prospect of genetic genocide as its likely conclusion. This is because, given the history of humankind, it is extremely unlikely that we will see the posthumans as equal in rights and dignity to us, or that

they will see us as equals. Instead, it is most likely either that we will see them as a threat to us, and thus seek to imprison or simply kill them before they kill us. Alternatively, the posthuman will come to see us (the garden variety human) as an inferior subspecies without human rights to be enslaved or slaughtered pre-emptively.

It is this potential for genocide based on genetic difference that makes species-altering genetic engineering a potential weapon of mass destruction, and makes the unaccountable genetic engineer a potential bioterrorist. This suggestion has been seen as overblown by some who favour the development of germline genetic alterations, but, given the history of humanity, the burden of proof should be on those who want to try to alter humans, rather than on those who oppose such a move.²² It has been suggested by others that germline genetics is unnecessary to produce a de facto two species result. James Evans, for example, has noted that simply depriving the poor of personalized genomic medicine “runs the risk of creating a genetically defined underclass which, because of inheriting more than a fair share of disease-susceptibility genes, is unable to afford adequate [medical] care.”²³

What should be done?

Bioethics has been called on to save us from the potential harms of the new genetics, but with its focus on individual decisions made in the context of the doctor-patient relationship, it cannot help us confront either global or species-wide issues. Although bioethics can help, and UNESCO’s new Universal Declaration on Bioethics and Human Rights is a step in the right direction of integrating human rights and bioethics, the language and practice of international human rights itself provides the most powerful approach to global governance of the new genetics.

In 2001 I suggested, with my co-authors Lori Andrews and Rosie Isasi, that the threat by cults and others, operating on the margins of human society, to clone a human being created an opportunity for the world to act preventively in ways that have been either extremely difficult or impossible. Specifically, I believed it was reasonable and responsible to suggest that UNESCO’s Universal Declaration on the Human Genome and Human Rights, and the overwhelming repulsion of peoples and governments around the world to the plan to clone humans, could be followed by a formal treaty on The Preservation of the Human Species.²⁴ Such a treaty would

ban species-endangering experiments, including cloning and germline genetic alterations. This does not mean that these techniques could never be used, but that no individual or corporation would be given the moral warrant to put the entire human species at risk without a worldwide discussion and a modification in the treaty. To the extent that it is concluded that the fear of genetic genocide is too extreme or overblown, the treaty could be time limited and expire automatically after the human species has gone, for example, 100 years without a genocide.

Species-endangering experiments (including the creation of new genetically-based bioweapons) directly concern all humans and should only be authorized by a body that is representative of everyone on the planet. These are the most important decisions our species will ever make. And they are of special concern to the human rights community. It is not that the human species is perfect the way it is (far from it), or that changes in humanity driven by evolution are not inevitable (they are). Rather it is that to the extent that human rights law is grounded in our understanding of what it means to be human, changing the nature of humanity at least puts at risk our understanding of human rights themselves.

We have a tendency to simply let science take us wherever it will. But science has become so powerful, both in terms of making our lives better and raising the risk of species suicide, that we can no longer abdicate our mutual responsibility to each other as fellow members of the human species.

Conclusion

It is currently completely illusory to believe, either that the new genetics are likely to do more good than harm to people in resource-poor countries, or that bioethics provides useful guidance to deal with genomic research in developing countries. We need a much wider, global framework, and a more inclusive language – human rights is suggested – to both promote social justice and inhibit discrimination. We must work together to promote genetic privacy, prevent the genetic engineering of humans, and promote and protect universal human rights-based on dignity and equality. Without action on the species level, genism based on pseudoscience will eclipse racism as the most destructive disease on the planet.

- * Portions of this chapter are adapted from a presentation at the UN World Conference Against Racism, Durban, South Africa, 31 August – 7 September 2001, UNESCO Forum on the Future, and ‘Genism, Racism, and the Prospect of Genetic Genocide’ 6 *Pacific Ecologist* (2003) 43–45.
- 1 For example, Maxwell Mehlman, *Wondergenes* (Indiana: Bloomington, 2003).
 - 2 University of Toronto Joint Center for Bioethics, ‘Top 10 Biotechnologies for Improving Health in Developing Countries’ (Toronto: University of Toronto, 2005).
 - 3 WHO, ‘Genomics and World Health: Report of the Advisory Committee on Health Research’ (Geneva: WHO, 2002).
 - 4 *Ibid.*, at 169.
 - 5 *Ibid.*, at 122.
 - 6 *Supra* note 2, at 6.
 - 7 *Ibid.*, at 8.
 - 8 *Ibid.*, at 86.
 - 9 *Supra* note 3, at 105.
 - 10 As quoted in Editorial, ‘Watson’s Folly’ 449 *Nature* (2007), at 948.
 - 11 *Ibid.*; C. Milmo, ‘Fury at DNA Pioneer’s Theory: Africans are Less Intelligent than Westerners’, *The Independent*, 17 October 2007, at 24.
 - 12 As quoted in ‘Genetics and Geneology: We are All Africans’, *The Times* (London), 17 November 2000, at 1.
 - 13 Natalie Angier, ‘Race is only Skin Deep’, *New York Times*, 22 August 2000.
 - 14 Sharon Begley, ‘Race is only Skin Deep So It Isn’t a Basis for Health Recommendations’, *Wall Street Journal Europe*, 1 August 2003, at 1.
 - 15 Natalie Angier, ‘Race is an Unscientific Concept, Experts Say’, *New York Times*, 30 August 2000.
 - 16 *Ibid.*
 - 17 J. Schwartz, ‘DNA Pioneer’s Genome Blurs Race Lines’, *New York Times*, 12 December 2007, A24. It should be noted that scientists now believe there is closer to a 0.5 percent variation than a 0.1 percent variation in human genomes.
 - 18 National Research Council, *Evaluating Human Genetic Diversity* (Washington, D.C.: National Research Council, 1997).
 - 19 For more on this project see <https://www3.nationalgeographic.com/genographic/>.
 - 20 E. Juengst, ‘Groups as Gatekeepers to Genomic Research: Conceptually Confusing, Morally Hazardous, and Practically Useless’ 8 *Kennedy Institute of Ethics Journal* (1998) 183–200.
 - 21 Quoted in Gregory Stock and John Campbell (eds.) *Engineering the Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children* (New York: Oxford University Press, 2000), at 79. Watson has also consistently argued against any sort of international agreement on genetic engineering: For example, “I think it would be complete disaster to try and get an international agreement. I just can’t imagine anything more stifling. You end up with the lowest possible denominator. Agreement among all the different religious groups would be impossible. About all they’d agree upon is that they should allow us to breathe air ... I think our hope is to stay away from regulations and laws whenever possible.” (*Ibid.*, at 87).
 - 22 G. J. Annas, L. Andrews and R. Isasi, ‘Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations’ 28 *American Journal of Law & Medicine*, (2002) 151–178. Updated in George J. Annas, *American Bioethics: Crossing Human Rights and Health Law Boundaries* (New York, Oxford University Press, 2005), at 43–58.
 - 23 J. P. Evans, ‘Health Care in the Age of Genetic Medicine’ 298 *Journal of the American Medical Association* (2007), at 2670–72.
 - 24 *Supra* note 22, and see George J. Annas, ‘The ABCs of Global Governance of Embryonic Stem Cell Research: Arbitrage, Bioethics and Cloning’ 39 *New England Law Review* (2005), at 489–500; and R. Isasi and G. J. Annas, ‘Arbitrage, Bioethics, and Cloning: The ABCs of Gestating a United Nations Cloning Convention’ 35 *Case Western Reserve Journal of International Law* (2003), at 397–414.

George J. Annas holds degrees in economics, law, and public health from Harvard University. He is the Edward R. Utley Professor and Chair, Department of Health Law, Bioethics and Human Rights, Boston University School of Public Health, School of



Law, and School of Medicine, Boston, MA, USA. He is the co-founder of Global Lawyers and Physicians, a transnational professional NGO dedicated to promoting human rights and health. His most recent book is *American Bioethics: Crossing Human Rights and Health Law Boundaries*, published by Oxford University Press, 2005.