

*Comments and Controversies*

**GENOMICS, HEALTH, AND SOCIETY\***

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**ABSTRACT**

On June 27, 2001, the World Health Organization conducted hearings in Geneva for a Special Report on Genomics & Health. Initially intended as a document to address the ethical, legal, and social implications of the gathering genomics resolution (ELSI), the terms of reference of the report were significantly modified to give primary emphasis to a scientific and technological assessment of the implications of genomics for human health. The Citizens' Health Initiative, one of two NGOs invited to make submissions at these consultations, suggested that no less important than the scientific and technical assessment was a perspective which gave due attention to the social context and political economy of scientific/technological development and its deployment. The article below touches upon neglected health priorities of poor countries, intellectual property rights and patents, risk management, insurance and discrimination, and predictive (prenatal) testing, reproductive choice, and eugenics.

The Citizens' Health Initiative (CHI) is a coalition of Non-Governmental Organizations (NGOs) based in Malaysia, which has extensive international links. We thank the World Health Organization (WHO) for this opportunity to express our views on genomics and health, and we wish to state the following as among our concerns:

\*Editor's Note: This is a position paper that was presented at the World Health Organization global consultations for a Special Report on Genomics & Health in Geneva, June 27, 2001.

## **1. JUSTIFIED EXUBERANCE OR GENOHPYE?**

Dr. Francis Collins, director of the U.S. National Human Genome Research Institute, has stated that the benefits from mapping and sequencing the human genome “would include a new understanding of genetic contributions to human disease and the development of rational strategies for minimizing or preventing disease phenotypes altogether” [1], with further prospects of “genetic prediction of individual risks of disease and responsiveness to drugs—and the development of designer drugs based on a genomic approach to targeting molecular pathways that [have] been disrupted in disease [pharmacogenomics]” [2].

We believe that a balanced assessment of the relative importance of genomics for human health is much needed, and this need not be confined to a developing world context. This debate is far from settled as is evident from the widely divergent views appearing in leading biomedical journals [3], set against the interplay of diverse etiological factors and the importance now attached to social determinants of health and disease, and health equity [4].

## **2. RE-INSTATING THE SOCIAL CONTEXT**

Over and above our deliberations on the potential and limitations of genomics for human health, we are no less concerned with the political and economic forces that have vast influence in shaping the priorities of its development and its subsequent deployment. This is especially so given a pervasive policy posture which favors privatization of health care and its financing, and the retrenchment of the public sector.

This fundamental dilemma, between need and economic demand, was lately dramatized by the campaign for affordable essential drugs, in particular, for anti-retroviral treatment for people living with HIV/AIDS.

We have seen how a profit-driven, market orientation can sacrifice a humane, lifesaving mission in order to cater to the dictates of shareholder interests and market pricing strategies [5]. Genomic-based enterprises will undoubtedly follow the same trajectory unless a pro-active campaign intervenes effectively to re-direct them more towards needs-based priorities [6].

## **3. NEGLECTED HEALTH PRIORITIES OF THE SOUTH**

The 10/90 Report on Health Research of the Global Forum for Health Research (Geneva, 2000) documented the gross imbalance between the health needs of poorer countries and the pitiful scale of research geared towards these needs. The imbalance in health care spending for services overall was equally bleak—nearly nine-tenths of the global burden of disease occurs in the poorer countries where only 1 in 10 health care dollars are spent [7].

In a recent interview in Lyon, France, Dr. Tikki Pang contrasted the enormous investment in genomics research with the funding levels for research on tropical diseases such as malaria [8].

Dr. Pang further remarked that what was needed to cope with the three leading killers in the developing world—malaria, diarrhea, and AIDS—were mosquito netting, cheap rehydration therapies, and condoms, none of which would become more available as a result of advances in genomics research.

It is doubly alarming that the very same forces pushing for privatization, for cost recovery in public health outlays, are undermining disease control efforts in developing countries. In Gambia, for instance, villages that were provided with insecticide free of charge for bednet impregnation, recorded a five-fold higher use of this proven malaria-preventive measure when compared to villages where user charges were introduced [9]. Households consistently cited lack of money as the main reason for families not dipping their bednets.

User charges introduced in Kenyan STD clinics similarly resulted in dramatic declines in patient attendance [10].

#### **4. INTELLECTUAL PROPERTY RIGHTS (IPR) AND PATENTS: LEGAL ARTIFACTS OF A CORPORATE-DRIVEN AGENDA**

Intellectual property rights and patents have been declared as indispensable pre-requisites for innovation and the introduction of new and useful commodities. Recent experience in the South, however, suggests that intellectual property law encourages not so much innovation as theft. We refer of course to the unrelenting efforts of biotechnology entities to privatize indigenous knowledge and genetic resources, appropriating what is essentially an evolved, cumulative heritage of human ecology. Among these instances of biopiracy are the following:

The granting of a patent (U.S. patent no. 5,663,484) for South Asian-derived basmati rice to RiceTec, Inc. of Texas [11], and the trademark jasmati for a potential hybrid between the long-grained aromatic basmati with the equally renowned jasmine fragrant rice of Thailand. The patent applies to breeding crosses involving 22 farmer-bred basmati varieties from Pakistan and India, and lays claim to such strains grown anywhere in the Western Hemisphere and marketed under the brand name basmati.

Basmati, sadly, is merely one instance of an escalating trend of biopiracy that has now engulfed plant materials from diverse sources—Mexican yellow beans [12], Bolivian quinoa [13], Andean nuna beans [14], Amazonian ayahuasca [15], West African sweet (brazzein) genes [16], Indian and Iranian chick peas [17], among others which have been well-documented by the Rural Advancement Foundation International (RAFI).

The failed attempt by University of Mississippi scientists to patent the oral and topical use of turmeric powder for ulcers and surgical wound healing, a long-established Ayurvedic medical practice [18].

The extraction and processing of azadirachtin from the neem tree for pesticide and other usage (another Indian traditional practice that WR Grace, Inc. succeeded in patenting) [19].

More directly pertinent to human source material and genomics-related intellectual property claims are the following:

The aborted attempt by the U.S. National Institutes of Health to patent a cell line derived from the Hagahai people of Papua, New Guinea [20].

Aside from cell lines with commercial value, gene sequences from populations with unusual disease frequencies are highly sought after in hopes of isolating disease-linked genes. On the South Atlantic island of Tristan da Cunha, for example, about 50 percent of the isolated and inbred population are either asthmatic or asthma-prone. The inhabitants of Kosrae, a Micronesian island in the South Pacific, have a high prevalence of obesity. Together with the Pima Indians of Arizona, who have high prevalence of both obesity and diabetes, they are prime targets for “obesity gene” hunters. As early as the 1980s, Dr. Cesare Sirtori of the University of Milan had discovered an unusual allele among residents of a small Italian village that seemingly conferred low risk of cardiovascular disease despite the subjects’ low levels of the protective high density lipoproteins (HDL). This allele (apo A-1 Milano) [21] was subsequently isolated, cloned, and patented in the attempt to develop a genetically engineered product to treat heart disease.

With the completion of mapping and sequencing of the human genome [22], the focus will now shift from genomic organization and its generic structure to studies of genomic diversity between and within populations, down to the level of single nucleotide polymorphisms (SNPs), and studies of multiple gene expression in healthy and diseased tissue samples using DNA microarrays. A prime objective, of course, is to correlate genomic differences (and gene expression data) with disease occurrence, a hugely expanded effort to identify putative disease-linked genes (and gene ensembles) with commercial potential. With or without the controversy-plagued Human Genome Diversity Project (HGDP), efforts will continue to collect genetic source material from diverse populations for research on genomic diversity.

In parallel with the development of biotechnology and genetic engineering, a legal armamentarium has emerged to bring the human body and its parts within the ambit of capitalist property relations. One significant milestone was the case of John Moore, a leukemia patient who underwent surgery in 1976 at the University of California for removal of his cancerous spleen. The Council for Responsible Genetics (Cambridge, Massachusetts) noted that “the University [of California] was later granted a patent for a cell line called ‘Mo,’ removed from the spleen, which could be used for producing valuable proteins [cytokines, including ones which mediate antibacterial and cancer-fighting activity]. The long-term commercial value of the cell line was estimated at over \$1 billion. Mr. Moore demanded the return of the cells and control over his body parts, but the California

Supreme Court decided that he was not entitled to any rights to his own cells after they had been removed from his body.”

This principle was re-affirmed in the New Jersey state legislature in 1996 when it enacted legal protections against genetic discrimination in employment and health insurance. This same legislature, however, also rejected a draft clause that would have declared individual genomic information to be individual, private property, with obvious implications for royalties and other benefits.

It is increasingly clear that “intellectual property rights” have largely become a corporate-defined artifact of law in capitalist society, often at the expense of individual as well as of community. As George Annas, professor of law and public health at Boston University, remarked, it is “bizarre that other people can own your genetic information [and body parts], but you can’t” [23].

## 5. RISK MANAGEMENT, INSURANCE, AND DISCRIMINATION

In October 2000, the Genetics and Insurance Committee (GAIC) of the U.K. Department of Health approved the use of genetic screening tests for Huntington’s disease in the assessment of life insurance premiums [24]. According to committee chairman John Durant, “This decision will mean that those with a negative test result will not be asked to pay more for life insurance because of their family history of Huntington’s disease.”

This puts a nice gloss to it, but on further reflection, those who test positive (and those who decline to be tested despite having a family history of Huntington’s) would have the entire risk premium loaded onto them. In effect, we’re back to the dilemma of risk-rated health care insurance: disaggregating an existing risk pool into sub-groups with differing risk profiles, so as to allow for profit-maximizing differential premiums for low-risk groups (“cherry-picking”) while marginalizing high-risk sub-groups as uninsurable. The net result is that those people at highest risk of falling ill and requiring treatment will be those least able to afford premiums, and therefore treatment.

These concerns take on added urgency with the worldwide trend towards privatization of the financing of health care, concomitant with an increased reliance on risk-rated health insurance. This fragmentation of community will be greatly exacerbated if insurance-mandated genetic testing is sanctioned and widely adopted [25].

It would be complacent to treat this as idle or alarmist fantasy. Hard on the heels of the U.K. decision [26], health insurers in Hong Kong are pushing for similar provisions under which “people shown in genetic tests to have a higher risk of developing specific diseases can have their insurance cover rejected or be forced to pay higher premiums. The [Hong Kong Federation of Insurers] said its members were not yet asking clients for the results of genetic tests, but they might soon start doing so as allowed under the code, which is based on the British version . . .” [27]. The deputy chairperson of the federation’s life insurance

council, Sarah Ho Sook-ming, further added that “once genetic tests for breast cancer and other diseases have proved to be technically reliable, we will have to ask for those results. . . .”

The Council for Responsible Genetics has quite correctly pointed out that genetic (disease) risks in a population, being fairly stable unlike the less predictable risks for infectious outbreaks, “are already reflected in the actuarial tables used by insurers to establish [premiums]. It is misleading for insurers to suggest that their financial solvency will be jeopardized if they are obligated to insure people at risk for genetic conditions. In fact, insurers have always insured people at risk for genetic conditions. Previously, however, it was not possible to identify those people before they became ill with the disorder. There is no reason for insurers to begin to use this new predictive information now, merely because it is available” [28].

What we observe in practice, however, is opportunistic (reciprocal) poaching of low-risk subscribers by competing insurers (identified by ever-more discriminating risk markers), which continually threatens to undermine any existing risk pool. This unfortunately is almost unavoidable with every new and more discriminating technology (such as DNA testing), which is introduced into a competitive, profit-driven setting. CHI is convinced that a sensible and civilized way of avoiding this deplorable situation, of stigmatized discards and social exclusion, is to move toward a re-affirmation of community through non-discriminatory social insurance, if not NHS-type nationalized or socialized health care.

## **6. PREDICTIVE (PRENATAL) TESTING, REPRODUCTIVE CHOICE, AND EUGENICS**

These are clearly among the most difficult and troubling of issues raised by the imminent proliferation of prenatal genetic diagnostics. Philip Kitcher, the American bioethicist, has authored a very nuanced and courageous book [29], suggesting that some form of eugenics is inevitable. Provided that it is voluntary and practiced on an individual basis without social coercion, the “utopian eugenics” that Kitcher envisages would attempt a fine balance between “compassionate abortion” (following upon prenatal diagnosis of severely disabling conditions and a very restricted future life) and maximally enabling services for the lives of future people with even the most severe medical conditions. He is sensitive to the interplay of social versus genetic constructions of “disability,” and to the dangers and contingencies illustrated by these hypothetical but not far-fetched scenarios of excess—if a genetic basis for left-handedness, for example, were ever demonstrated, would the higher mortality associated with this trait (plausibly from social more than physiological causes) dispose some parents to abort a less than “perfect” or “defect-free” child? Could fetuses bearing a “homosexuality gene” suffer the same fate?

These are clearly very contentious issues over which consensus may only emerge, if ever, after protracted, iterative deliberations, and even then will be

highly contingent on social and historical context. Crucial to this will be the social circumstance and process adopted in seeking a popular consensus that does not ride roughshod over minority rights.

## **7. GENETICALLY MODIFIED (GM) CROPS**

We note the ACHR's request that further discussion on genetically modified crops be deferred to other occasions and settings. While biosafety and environmental impacts of GMOs are also addressed by other agencies such as FAO, we consider that it is quite appropriate for WHO to evaluate and to advise upon the health aspects of genetically engineered food.

On this issue, CHI takes note of the very legitimate concerns raised by scientific and lay communities [30, 31]. In line with the precautionary principle, we support an indefinite moratorium on the further dissemination of genetically modified crops.

## **8. A POLICY RE-ORIENTATION FOR RESPONSIBLE AND EQUITABLE GENOMICS**

We urge the WHO to lend its moral authority in support of all the above concerns. We call on the WHO to re-assert its international leadership in crucial areas of health policy such as the organization and financing of health care. Health care must remain as a collective social responsibility, not a service to be delegated to the market as arbiter of access. CHI notes that the Director-General, Dr. Gro Harlem Brundtland, had affirmed in the 1999 World Health Report that "not only do market-oriented approaches lead to intolerable inequity with respect to a fundamental human right, but growing bodies of theory and evidence indicate markets in health care to be inefficient as well."

In the few years since then, even more evidence has emerged to confirm the poor track record of market-driven health care (and of its soft-edged cousin, managed competition), judged on equity as well as on efficiency grounds [32-35].

It is deplorable that international agencies such as the World Bank, International Monetary Fund, and the World Trade Organization can continue to advocate the dismantling of public-sector health care out of an obsessive faith that market-based solutions will invariably deliver higher efficiency and lower unit costs, clearly not the case in many instances.

We call on the WHO to take all necessary steps to promote access to primary care-led health services on the basis of need, and not on the ability to pay. This is the only meaningful stance consistent with a declaration of health care as a human right. We are mindful of the reality that health care up to a point will be rationed, but we are equally firm in our view that rationing by the market is completely unacceptable.

Recognizing that the WTO threatens to ride roughshod over health concerns in international trade, the WHO should support any moves to take health-related services out from under the ambit of WTO-GATS regimes, and to further loosen the grip of WTO-TRIPS on access to essential drugs and other life-saving items.

We call on the WHO, an organization of member states but increasingly subject to corporate influence, to create more space for the meaningful participation and inputs of popular organizations in international health policy advising and agenda-setting. We believe that these are some of the important pre-requisites for an equitable harvest of benefits that are possible from a humane and responsible development of genomic technologies.

#### ENDNOTES

1. F. S. Collins. 1999. Shattuck Lecture—Medical and Societal Consequences of the Human Genome Project. *NEJM* 341:28-37.
2. F. S. Collins and V. A. McKusick. 2001. Implications of the Human Genome Project for Medical Science. *JAMA* 285(5).
3. F. S. Collins. 1999. Shattuck Lecture—Medical and Societal Consequences of the Human Genome Project. *NEJM* 341:28-37; NA Holtzman and TM Marteau. 2000. Will Genetics Revolutionize Medicine? *NEJM* 343 (2):141. (Correspondence: *NEJM* 343 (20):1496—J. G. Sotos, H. Y. Rienhoff Jr., G. D. Block, M. P. Aulisio, M. J. Khoury, B. A. Ference, M. S. Chauhan, S. Izumo, N. A. Holtzman, T. M. Marteau); R. Hubbard and R. C. Lewontin. 1996. Pitfalls of Genetic Testing *NEJM* 334 (18):1192. (Correspondence *NEJM* 335 (16):1235—H. J. Stern, A. Maddalena, J. D. Schulman, W. D. Foulkes, H. F. Bunn, T. P. Stossel, B. G. Forget, G. Stamatoyannopoulos, D. J. Weatherall, R. Hubbard, R. C. Lewontin.)
4. T. Evans, M. Whitehead, F. Diderichsen, A. Bhuiya, and M. Wirth (eds.), 2001. New York: Oxford University Press; P. Braveman, N. Krieger, J. Lynch. 2000. Health Inequalities and Social Inequalities in Health. *Bull World Health Org* 78: 232-234; D. Leon and G. Walt (eds.). 2000. *Poverty, Inequality and Health*. Oxford: Oxford University Press.
5. Lifting the Curtain on the Real Costs of Making AIDS Drugs *New York Times*, April 24, 2001; A Turning Point That Left Millions Behind. *Washington Post*, December 28, 2000.
6. The HIV genomic sequence, known since the mid-1980s, brought little benefit to impoverished HIV-infected persons in the South until an effective campaign was mounted by Medecins sans Frontieres, South African Treatment Action Campaign, and Oxfam for affordable anti-retroviral treatment.
7. C. J. L. Murray and A. D. Lopez (eds.). 1996. *The Global Burden of Disease*. Vol.1, p. 254. Geneva: WHO (in conjunction with Harvard School of Public Health and The World Bank).
8. Advances in human genome research could widen North-South gap. IPS, February 12, 2001.
9. Reported in Phasing Out User Fees. Robert Weissman, *Multinational Monitor*, December 2000.
10. S. Moses, F. Manji, J. E. Bradley, et al. 1992. Impact of user fees on attendance at a referral centre for sexually transmitted diseases in Kenya. *Lancet* 340: 463-466.

11. Basmati Rice Patent: The (Merchant) Prince and the (Punjabi) Paupers. *RAFI News*, April 1, 1998.
12. “. . . [I]n the spring of 1999 Larry Proctor, owner and president of POD-NERS L.L.C., a small seed company, won both a U.S. patent (No. 5,894,079) and a U.S. Plant Variety Protection Certificate (No. 9700027) on the Enola bean which was derived from the “Azufrado” or “Mayocoba” Mexican varieties. The patent claims exclusive monopoly on any *Phaseolus vulgaris* (dry bean) having a seed color of a particular shade of yellow. POD-NERS is now suing Mexican bean exporters charging the Mexican beans they are selling in the U.S. infringe their U.S. patent on the yellow-colored bean variety . . .” *RAFI News*, January 17, 2000.
13. “. . . Quinoa (*Chenopodium quinoa*) is a high protein food crop that is an important part of the diet of millions in Andean countries, especially indigenous people. Since pre-Incan times, indigenous people in Argentina, Chile, Bolivia, Peru, and Ecuador have been developing varieties of quinoa suitable for the wide variety of harsh conditions in the Andes. In particular, they have developed quinoa plants that can tolerate high altitude, low temperatures, little rainfall, and poor soils. In recent years, quinoa has entered the U.S. and European marketplace as a little-known, but increasingly popular “ancient grain” that is exceptionally nutritious. (Barley, maize, and rice have less than half the protein of quinoa). In 1994, agronomists Duane Johnson and Sarah Ward of Colorado State University received U.S. patent no. 5,304,718, giving them exclusive monopoly control of male sterile plants of the traditional Bolivian “Apelawa” quinoa variety and its use in creating other hybrid quinoa varieties. Duane Johnson readily admits that he and Sarah Ward did nothing to create male sterile varieties of Apelawa quinoa, “It’s part of the native population of plants,” explains Johnson, “we just picked it up.” The U.S. patent claim is not limited to a single hybrid variety, it claims any quinoa hybrid that is derived from Apelawa male sterile cytoplasm, including many traditional Andean varieties . . .” *RAFI Communique*, December 30, 1996. In May 1998, after a protracted fourteen-month campaign, Andean farmers succeeded in forcing Colorado State University to surrender the “Apelawa” quinoa patent.
14. Bracing for ‘El Nuna’: Andean Groups Hopping Mad About Popping-Bean Patent. *RAFI News*, March 20, 2001.
15. “. . . [I]n 1995 RAFI disclosed that Loren Miller, a U.S. citizen, had obtained a U.S. patent on *Banisteriopsis caapi* (patent #5751), a plant species native to the Amazon rainforest. Popularly known as the Ayahuasca vine, the plant is used in sacred indigenous ceremonies throughout the Amazon, where it is well-known for its medicinal and hallucinogenic properties. In November 1999, the U.S. Patent and Trademark Office (PTO) rejected the ayahuasca patent. The PTO’s decision came in response to a request for re-examination of the patent in March 1999 by the Washington DC-based Center for International Environmental Law (CIEL), on behalf of the Coordinating Body of Indigenous Organizations of the Amazon Basin (COICA) and the Amazon Coalition. The groups requested that the patent be cancelled because the claimed patent lacks novelty and distinctiveness, is found in an uncultivated state, and is a sacred element of many indigenous cultures of the Amazon and should not be subject to private appropriation . . .” *RAFI Communique*, May 11, 2000.
16. “. . . University of Wisconsin scientists are now making money from their patents on ‘brazzein’ a super-sweet protein extracted from the berries of a West African plant,

*Pentadiplandra brazzeana*. The Wisconsin scientists ‘discovered’ the super-sweet berries in Gabon, where local people have known and consumed the berries for many years. Despite being the inspiration and origin for brazzein, neither Gabon nor its people will share the benefits. University of Wisconsin scientists won four U.S. patents on the brazzein protein between 1994-1998. They were the first to isolate, sequence, and synthesize the DNA encoding for the production of *P. brazzeana*’s sweet protein. The breakthrough in synthesizing the brazzein protein, and the ability to produce it in high-tech laboratories, essentially eliminates the need for *P. brazzeana* to be collected or grown commercially in West Africa as a source for the super-sweet protein. Brazzein is reportedly 2,000 times sweeter than sugar, a quality that makes it highly desirable as a natural, low-calorie sweetener. Corporate interest in brazzein is strong. The low-calorie, dietetic sweetener market represents a wholesale value of U.S. \$1.4 billion worldwide . . .” *RAFI Communique*, May 11, 2000.

17. “. . . [T]he Australian seed industry has applied for plant breeder’s rights (PBR) on two chick pea varieties taken from ICRISAT (International Crops Research Institute for the Semi-Arid Tropics), an internationally funded public research center based in Hyderabad, India. If granted, the Australians will give themselves a 20-year monopoly on the Asian chick peas, which they propose to market in South Asia and the Middle East. Neither variety, however, is new to farmers. In fact, both are ICRISAT accessions originating in farmer’s fields in Iran and India . . .” *RAFI News*, January 6, 1998.
18. *Nature* 389:6. September 4, 1997.
19. Vandana Shiva. *The Neem Tree—A Case History of Biopiracy*. <http://www.twinside.org.sg/title/pir-ch.htm>
20. Members of the tribe are infected with a unique strain of human T-lymphotropic virus-1 (HTLV-1), which is potentially valuable in diagnostic tests and vaccine development for leukemia-related diseases. Another patent claim (Wÿ-9215325-A) with similar potential was filed for the human T-cell lines of a 40-year-old woman and a 58-year-old man from the Solomon Islands. In late 1996, the NIH abandoned the patent application (Publication Number WO93/03759). Nonetheless, the Hagahai cell line is now being sold by the American Type Culture Collection as ATCC Number: CRL-10528 Organism: *Homo Sapiens* (human) for \$216 per sample. The Solomon Island cell line as well as another cell line derived from the Guyami people of Panama are also deposited there.
21. Coding for a mutant Apolipoprotein A-1 which turned out to be efficient at scavenging cholesterol from arteriosclerotic plaques for disposal via the liver’s metabolic processes.
22. The Human Genome Project sequenced an “average” genome of a “typical person.” This “typical person” is a compilation (composite) of 20 to 30 individuals anonymously selected from hundreds of subjects who, given the demographics of the volunteers used for this project, are thought to be primarily of Western European descent.
23. *Nature*, November 21, 1996. [It is akin to saying: I have a sophisticated technology that can mine this exotic mineral found within your borders. Insofar as you cannot extract it yourself, you deserve no part of the benefits from my successful exploitation of this mineral, which should be considered a “commons resource” in the “global public domain.”]
24. Decision of the Genetics and Insurance Committee (GAIC) Concerning the Application for Approval to Use Genetic Test Results For Life Insurance Risk Assessment in Huntington’s Disease. [UK Dept. Health] GAIC/01.1. October 13, 2000.

25. Over and above this atomization of society, fear of genetic discrimination can also deprive people of the real benefits of genetic testing. Unless there is effective protection against post-test discrimination, many people may avoid genetic testing out of fear that the test results would be used against them. This could result in their missing out on the benefits of early diagnosis, treatment or prevention (for example, risk reduction through avoidance of etiological co-factors).
26. There is some indication of backtracking from the GAIC decision of October 13, 2000—U.K. Moving Toward Ban on Gene Tests by Insurers (*International Herald Tribune*, May 2, 2001). In the February 2001 issue of the *Journal of the Royal Society of Medicine*, Anna Dixon and her colleagues at the London School of Economics critically reviewed the GAIC decision, noting that Austria, Denmark, the Netherlands, Norway, and France have imposed legal restrictions on insurers' use of genetic test information while 28 states in the U.S. have either restricted or banned the use of genetic data for underwriting purposes.
27. Insurers review gene-test code. *South China Morning Post*, April 23, 2001.
28. Genetic Testing and Life and Disability Insurance [http://www.gene-watch.org/programs/GD-FAQ-Life\\_Ins](http://www.gene-watch.org/programs/GD-FAQ-Life_Ins)
29. P. Kitcher. 1996. *The Lives to Come. The Genetic Revolution and Human Possibilities*. New York: Simon & Schuster.
30. 13 Myths About Genetic Engineering. <http://www.ipcb.org/news/myths.html>
31. Frequently Asked Questions About Genetically Engineered Food. <http://www.gene-watch.org/programs/FAQ-Food.html>
32. Donald Light (ed.). 2001. Comparative Studies of Competition Policy. *Social Science & Medicine* 52(8) (special issue April 2001) . . . “a set of comparative case studies from the U.K., Netherlands, Sweden, southern Europe (Greece, Italy, Portugal, Spain), Israel, New Zealand, and Latin America (Argentina, Brazil, Chile, Ecuador) to illustrate how governments and institutions responded to pro-competition health care policies during the 1990s. Most began with enthusiasm and then drew back as they realized the danger of greater costs (rather than less), more inequality, dislocations, and back-door reductions in coverage. The few that carried out competition reforms experienced a political backlash and defeat at the next election.” (Editor's summary).
33. S. Woolhandler, D. U. Himmelstein. 1999. When Money is the Mission—The High Costs of Investor-owned Care. *NEJM* 341 (6):444.
34. C. K. Chan. 2000. Privatisation, the State and Healthcare Reforms: Global Influences & Local Contingencies in Malaysia, paper presented at the 9th International Congress of the World Federation of Public Health Associations, Beijing, People's Republic of China, September 2-6, 2000.
35. Briefing Note for the U.K. General Election on Health and Privatization. Allyson Pollock, David Rowland, Neil Vickers, University College, London, May 24, 2001.

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