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Emerging Normative Problems of Genomics

The administrators of the human genome project were eager to stimulate public discussion, academic debate, legal and legislative deliberation of how individuals and institutions should respond to the revolution in genomics. Paramount among the issues whose discussion they encouraged are three obvious matters:

The threat which access to our genetic information poses for health insurance, employment, and social discrimination

the nefarious consequences for scientific advance of turning basic scientific discoveries about genomes into private property

The permissibility of prenatal genetic screening, germline therapy, cloning and other in- vitro reproductive processes.

It should not be surprising that there is a great deal of uniformity of views about most of the problems that come under these three headings. For they do not raise issues different in kind from those we faced in bioethics before the genomic revolution. Even starting from divergent moral theories, by and large people have come to broadly similar conclusions about which newly available choices are morally permissible and which are not. Our moral intuitions and articulated moral theory have stood us in good stead, providing substantial grounds for disapproving new genomically inspired examples of old practices—like eugenics, the paternalism of health-care experts, and the sacrifice of individual rights to

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larger community interests. In most cases, the morally central idea has been to preserve individual autonomy whenever it has come under threat, from the non-moral forces of private interest, and from moral forces such as general public or individual welfare.

What has been insufficiently discussed is not the question of what is the morally right thing to do in the light of the genomic revolution, but three other questions: first, what people will in fact do, second, what will be the worst case consequences of people's actual choices among the startling new options genomics puts at their disposal, and third, how we should design our institutions to protect ourselves, them, and our children from the worst consequences of these actual choices. In this paper, I identify three new scenarios I anticipate we will face in the medium term future as a result of choices among alternatives genomics presents to people, and I explore how our political culture can feasibly and effectively respond to mitigate their morally undesirable outcomes. I think these are the hard new questions the genome raises. If you think some of these scenarios are "science fiction" cases no one ever need worry about, think about cloning.

One thing we know for certain. We cannot legislate agreement on morality, and when we try we find that we cannot enforce it. Indeed, enforcement of morality often results in effective strategies to circumvent enforcement, sometimes so effective as to facilitate even more of the actions we may agree are impermissible. Consider how the strictures against abortion led to RU488 and thus to a much larger number of pregnancy terminations than there would have been in the absence of such strictures. In many cases the only socially feasible, let alone the only morally permissible way of ensuring that people make the right choices is to provide significant carrots–incentives, as opposed to sticks–threats of punishment. When strong enough incentives are unavailable, we must sometimes simply reconcile ourselves to mitigating undesirable outcomes we cannot prevent. This will, I think, often be the case when we craft

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policy to respond to the way people will in fact act when genomics gives them new opportunities. Given the wide-spread agreement on what the right, the good, and the just are, and the recognition that people often fail to act rightly, justly or for the good, when it conflicts with their individual self-interests, public debate should focus on the design of institutions that will give people incentives to do “the right thing”, or at least avoid the wrong thing.

What is new about the implications of genomics are the opportunities it presents people with to exploit our society’s commitment to individual autonomy with consequences that very greatly reduce general and individual human welfare. It is these outcomes we need to figure out how to avoid.

#### 1. Coping with the inevitable market in child-design

There will eventually be opportunities to choose children’s gender, size, appearance, behavioral traits—including intellectual, emotional and athletic traits. Anyone who doubts the claim about behavioral traits has only to examine what has already been learned from gene-knock out studies about the genetic basis of such complicated mammalian behaviors as female nurturance and male infanticide.

There is no way to prevent the emergence of techniques for designing children, because they are the unavoidable by-products of techniques needed to prevent genetic defects. Once invented, there will sufficient demand that a market in them will emerge. If forbidden in one jurisdiction, child design will flourish in another. And in any case it will persist underground in the jurisdictions where it is prohibited. Compare the instantaneous emergence, of a black market in human growth hormone among those who want NBA-sized children, once Genentech began manufacturing Humulin. What is the expected outcome of a market in child-design? Well, among some groups, there will be a shift in the sex ratio to males, among others there will be a large number of kids who look like Barbie and Ken. And of course people will seek economically valuable genetic traits for their children just as they now make sacrifices

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to secure environmentally determined advantages for them. There will probably also be a further decline in the birth rate among affluent people who design their children, as they will get exactly what they want by way of children's traits "the first time out."

A seriously skewed sex ratio—insufficient numbers of females for available males—would of course lead to serious social instability and eventually to increased sexual violence, as India and China may show us in the next few years. And a sharp increase in certain traits now rare might lead to a decline in their price: if there were 10 times as many NBA sized athletes available, the average salary of an NBA player would decline (or they would change the rules). And in a sea of Kens and Barbies, someone neither blond nor tall might be more attractive. But compared to these athletic and cosmetic outcomes, the one thing we can be certain of is that existing inequalities in wealth and income and their concomitants will be increased generation after generation, by the existence of a market in child design. Start with the current genetic lottery and an approximate equal-opportunity meritocracy of the sort contemporary western societies aspire to, in which greater incomes reward the talents and skills the society demands, most have an about equal opportunity to earn these rewards and there is consequently a significant turnover through the income strata in each generation. It is the roughly equal opportunity and approximate meritocracy of our economy which reconciles the less well-off to the income inequalities they see around them. Now add the power of the currently wealthy to rig the genetic lottery, to design children who will win the meritocratic race, and the result after a few generations will be the end of all circulation through society's income strata. Designed children will not have earned their advantages any more than Prince Charles' kid, Harry and William, have, perhaps less if the genetic lottery can be thoroughly rigged. If the meritocracy ever existed, it abolishes itself. Instead income inequalities come to be clearly unearned, and there is no circulation through the income elites.

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We are both morally and prudentially committed to an equal opportunity meritocracy. Prudentially, we know that its abolition is the path to civic unrest; recall the slogan “No justice, no peace” Morally, the meritocracy of earned differences is the only justification for the degrees of inequality our society peacefully tolerates. We cannot afford to do without it. How do we prevent the inevitable market in child design from destroying the meritocracy by skewing the genetic lottery?

We cannot preserve the meritocracy through a blanket prohibition of a market in child design, short of imposing a police state, or restricting travel abroad. The prospects for effective prohibition are not much different from those for prohibiting the use of narcotics.. So, if we can’t make child design impossible, can we make it so difficult that the problem becomes tolerable? Not without violating the autonomy of parents in making decisions about the best interests of their children. Surely we are not going to remove designed children from their homes or impoverish them with draconian fines against their parents;. Indeed, do we really want to penalize parents whose motives are quite selfless and directed at the advantages of their children? We don’t forbid parents to make great sacrifices to provide non-genetic benefits to their children later lives.

How do we craft a policy that will save the meritocracy without interfering with basic parental rights? Consider the following policy response to the emergence of a market in child design. First, impose substantial and long term excise taxes on parents who procure genetic advantages for their children. By substantial I mean taxes levied at a rate several times the actual cost of the procedures. This will reduce the demand for all but the economically most valuable traits. Second, employ the revenue created to make available the same procedures without the associated excise taxes to those below a certain income level. Such a tax will have the effect of significantly increasing the number of people in each generation who have these traits which the society rewards. The result of an increased supply will

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be a decreased economic return to such people, and a mitigation of the income inequalities that the child design market will produce. The result would preserve some proportion of the meritocracy and ensure a continued circulation through the income elites. Third, in order to avoid a black-market in child design, or an off-shore market in it, the state will have to subject all parents and children to genetic testing and impose punitive fines as well as back-taxes for those who violate the regulations by procuring child design without paying the taxes..

This last enforcement provision is crucial to the effectiveness of the policy. And here of course we see emerging one of the continuing problems that the revolution in genomics exacerbates. For it is clear that genetic testing on the scale required to enforce anything like a level playing field in the face of a market in child design threatens the privacy of every one's genetic information. We can't selectively enforce genetic testing only on "suspects", and we probably cannot establish baseline data that would enable us to tell whether a child's genetic endowment is inherited or purchased, without data on many, perhaps most, or even every one in the population.

Aside from all the rest of the violence we will have to do to parental autonomy, is preserving the meritocracy worth the abrogation in privacy rights? Probably. For the alternative to a meritocracy is probably something approaching Hobbes' state of nature.

## 2. Killing the golden goose because we can't afford to wait for more golden eggs

First a little political philosophy. Enlightened liberal and even radical figures have accepted the need for private property as the only solution to the tragedy of the commons: a scarce resource held in common by a number of people will be quickly depleted owing to the temptation of each to free ride on the other's restraint and the recognition of each that self-restraint in the face of free-riding is irrational.

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The trouble that dividing the commons into private plots leaves nothing for later arrivals. This is a serious problem when it comes to justifying private property. If there is nothing left for those who arrive late through no fault of their own, the ownership of property may be deemed unjust.

300 years ago John Locke offered a partial solution to the problem of justifying private property which has yet to be improved upon. According to Locke's formula the first or original acquisition of private property consists in "mixing one's labor" with nature, provided that one leaves as good and as much for others. The proviso about leaving as good and as much for others is obviously the hard condition to satisfy. But it is interesting to note that this proviso is perhaps easiest to satisfy in the case of "intellectual property"—ideas in people's minds. If any resource is in undepletable supply it is ideas, and the only way to originally acquire a good idea is to mix one's intellectual labor with it..

Now, a little economic theory. It has long been obvious to economists that ideas raise a particularly clear version of the tragedy of the commons problem. If good ideas—for example, labor saving inventions—are part of a common stock of resources to which all have equal right, then in many cases no one will have much incentive to invest in the effort, resources and time it takes to produce these good ideas. For once one person figures out a clever short cut, every one else can appropriate it—copy it—without having made any investment in time, thought, and effort to invent or discover it. So every one has an incentive to hang around waiting and watching for someone to reveal a good idea they can copy. Result: with every one waiting around to copy, few good ideas will emerge. On the other hand, consider an environment in which every one is in competition with every one else and all need to solve some urgent problem. Here, the competition breeds secrecy, and the secrecy breeds over-investment in the search for a solution to the problems. If everyone knows that the first discoverer will not share the solution but keep it secret in the interests of winning the competition, then every one will

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try to come up with the good idea. So, the competitors are on balance worse off, both because they collectively over-invest in seeking a solution, thus using resources with other uses, and they can't force the discoverer to sell them the good idea at a price they can afford. Thus when it comes to investment in new ideas the outcome is always either too much or too little total investment.

The solution to this problem is of course the patent-right: in exchange for mandatory disclosure of the good idea, the discoverer is awarded an exclusive right to sell it for a limited period. The combination of mandatory public disclosure and the exclusive property right are both essential if we are to solve the problem of under-investment in seeking some new ideas and overinvestment in finding others.

Whether information about individual nucleotide sequences that code for important proteins and enzymes can be private property or not has been settled in a couple of different ways, and with some interesting qualifications by the three principle patent agencies in Japan, the European Union, and the United States. Broadly the answer is yes, some basic scientific ideas can be held as private property, at least for 17 years or so. And the reasoning behind the yes answer reflects the argument I sketched above about the benefits to society at large of privatizing information as a solution to the overinvestment/underinvestment problem.

But much of the information that Genomics provides has another feature: it has huge consequences for the health and well-being of large, very large numbers of people, and in some cases for immediate questions of the survival of these large numbers. This means that sooner or later, probably sooner, the private-property solution to the problem of encouraging genetic research will come into conflict with our commitment to maximize human welfare. The conflict will require an entirely new solution to the problem of encouraging scientific and technical innovation by providing patent rights.

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To see the problem, we need only consider a headline story of early 2001. Perhaps you will recall the proposal in the parliament of the Republic of South Africa to abrogate patent rights on a variety of AIDS drugs owing to a rate of HIV positive incidence in a population untreatable at prevailing drug prices, the eagerness of an Indian company to pirate these drugs, and the eventual cave-in to lower prices of the principle drug companies involved.

Now consider most pressing world wide illnesses: malaria. Suppose that as a result of the expenditure of very large capital sums to sequencing the anopheles mosquito genome, a private firm is able to patent and sell a vaccine for malaria. And what is equally probable, assume that the rate of malaria infection in Africa is very high, that the ease of copying the vaccine encourages governments to threaten to abrogate the patent for the vaccine, even at the costs to them of banishment from the World Trade organization. The threat alone will force price reductions even though it makes it impossible for the company to sell its product at a price that will repay its capital costs of designing the resulting product. At a reduced price the company will at least be able to pay off some of its costs, and reduce its loss. But there will be one more consequence. The company will never again direct its research at a third world disease. Instead, it will focus on treatments for baldness, impotence, acne, wrinkles, and the chronic diseases of the rich. Widespread undeniable human needs will be so great that they will force us to kill the geese that lay the golden eggs.

For all we know, this outcome may already have been fixed by the actions of the government of South Africa and the Indian pharmaceutical company prepared to copy the anti-AIDS drugs in question.

One solution that will occur to many people is government supported scientific and technical research the results of which cannot be privatized. This policy is already in place for important parts of

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genomic research. Researchers supported by US, UK and other government grants are required to openly publish their gene sequence data soon after securing it. But to solve the problem in question, government support and regulation will have to move beyond basic science and into technical application. That is, the government will have to decide which research questions in applied science to pursue, in what order, by which scientists, exploring which hypotheses. And the track-record of this sort of government action is not at all good. Consider the poor track record in applied scientific innovation of the centrally planned economies of eastern Europe and the Soviet Union. Perhaps more to the point, consider the on-going war on cancer declared by US President Nixon in 1969, or the failure of Japanese Ministry of International Trade and Industry, MITI, successfully to direct scientific and technological innovation at a time when Japan had a substantial advantage in resources, technological infrastructure, and world class science. The failure was the result of the fact that of all the factors that influence economic growth, the one which is most completely “exogenous” in the economist’s lingo, unpredictable and uncontrollable in its appearance and its impact, is “technological improvements” a.k.a. scientific discovery and innovation. Offering a university, research institute, or drug company a contract to make a new discovery is impossible. Do they return the money if they fail? Offering a contract without an expected outcome is a prescription for waste of the sort governments are good at generating.

Another partial solution to the problem would be to allow the owners of drug-patents to charge different prices for the same products in different markets, to permit “price discrimination”. By selling below cost in the third world, and above cost in the developed world, patent-holders would make more money than they would if pirate-drug companies were supplying the third world demand. There are two problems with this solution: first, we have to explain to people in developed countries why they should

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pay more for the same thing sold at a tenth the price elsewhere; second, a black or a grey market is certain to spring up, in which drugs produced for and sold in the third world make their way back to the first world at prices somewhere between the first world retail price and the third world's subsidized price, thus reducing further the drug companies' return and the impact of the needed drugs on health in the countries for which they were manufactured.

**In the long run**, of course, protecting patent rights as absolute, will, with the highest probability, provide the innovations every one needs, across all levels of economic development, and all health needs. Market forces are like that--in the long run they distribute scarce resources in economically optimal ways. Unfortunately, in the long run we are all dead, and our problem is to find a policy that will mitigate our problem in the **medium term**, before all currently alive present and future malaria victims are dead.

Another apparent solution that mirrors politically accepted practice in other cases is the exercise of "eminent domain". Just as the state has the right to expropriate and compensate individuals for their tangible property in the public interest, it presumably has the same right in the case of intellectual property. The trouble is that information is so different from tangible property that employment of this policy except under the most exceptional circumstances may have the same effect on third world health needs as a policy of no intellectual private property at all. The threat of expropriation will discourage pharmaceutical companies from making heavy investments in treatments for the most epidemic illnesses; Moreover, there is the question of how can we fix, and who will pay the price for expropriated intellectual property. As with genetic enhancements, we might tax the consumption of luxury goods, like genetic cures for baldness or facial wrinkles, though it is doubtful enough money could be raised this way. But who will impose this transnational tax, and who will enforce its collection? Moreover, unlike

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tangible goods there is nothing approaching a market for equivalent property from which the value of a cure for a third world disorder like malaria can be inferred. This proposal has all the same difficulty as that of establishing a just price for pollutants, and enforcing international agreements to reduce global warming.

Recall the first solution broached above: invite first world governments to subsidize their own scientists research into third world diseases, to patent the discoveries so that private concerns cannot do so, and to subsidize the manufacture and distribution of these drugs as a form of foreign aid. This is a highly imperfect second, third or even fourth best solution. For it does not allow for the sort of scientific and technical development which a free-market in ideas can foster. It sets the research agenda by a combination of needs' assessment and educated guesses about the near term course of research, both conducted by central planners without anything like complete or even current information; it compensates scientists by the quality of their pedigrees, past research, grant-writing skills and personal connections, and so discourages unanticipatable innovation from novel sources. And it adds whatever bureaucratic burden government usually adds to the cost in money, quality, and timeliness of the products produced. Finally, as we know from the current level of first world foreign aid, the resources that can be expected to be devoted to such projects will be far below the level of need.

### 3. Will we want privacy; should we want it?

First a question of moral philosophy: do we each own the information about our separate genetic endowments? Does this information belong to us? Is it our private property? Well, on Locke's theory, which provides the best available moral justification of intellectual property, the answer is pretty clearly no: we do not own information about our bodies. Why? First of all, we do not mix our labor with

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the information, unless we sequence our own genomes and then do the computational genomics to identify the genes we bear. If any one owns the information it is the employer of persons who processes (mixes their labor with) a drop of our saliva or a corpuscle of our blood to secure this data. Second, in those extremely exceptional cases where a scientifically, clinically, or commercially valuable genetic sequence emerges from a patient's body, the material is so close to unique that nothing even remotely like it is left for others. So, no mixing of labor, nothing as good and as much left for others, *ergo*, no private property, no right to ownership. To these considerations against ownership of information about our genetic information we can add a few more. The information about any one person's gene sequence is by itself commercially and scientifically valueless to that person or to any other person. It is of value only when aggregated along with information about many persons' sequences and their medical history. Ironically the more genetic information we aggregate, the greater the value of the aggregated information to each individual and the lower the need for any one individual's information. So, by itself each individual's raw gene sequence data is not owned by any one and has no value to any one.

On the other hand, whether we own it or not, in the present and foreseeable political culture, we do have effective control over this information, and we have strong incentives to exercise control over it. Indeed, such strong incentives to control its dissemination that sometimes people don't even inform themselves about their genetic, lest the information also fall into hands that could harm them. In the present state of things, availability of information about a person's genetic inheritance can harm one in several ways: the three most obvious being a) employment discrimination, b) social stigmatization, and c) access to health care insurance. For this reason, governments everywhere in the developed world have been pressed to impose regulations that forbid the sharing of genetic information without the consent of the person from whom it comes.

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It is the last of these—the health insurance issue—on which many commentators have focused, demanding ever stronger safe-guards for privacy. And yet for most people in the developed world, privacy about genetic endowment is probably a barrier to the best health care, while openness about health care can provide a benefit

In most health insurance regimes, privacy of genetic information imposes a cost in health care, and openness provides a benefit. All national health care schemes, and almost all private health care schemes, are not-for-profit programs based on “community rating”—that is, the cost of premiums or tax payments to secure coverage is determined by the average cost of treatment over the entire community covered, and not the actual cost of treatment for individuals paying premiums. Unlike the case of life-insurance, charges for group health insurance, are not based on the insurer’s risk in individual cases. So, there is no threat of denial of coverage for a genetic disorder. Of course genetic information will in the long run eliminate the market for supplemental health insurance based on individual risk, owing to adverse selection and probably moral hazard as well: as people’s genetic information about themselves increases, those at greater risk will seek more insurance, those at lower risk will seek less, and some of those insured will take risks they would not otherwise take just because they are insured against them. This process must destroy the profitability of private supplemental health insurance. But the same forces will also shift us from private to public health insurance.

In nations with national health insurance, genetic information will have no effect on coverage. In countries with private group health insurance, the medium term impact of wide-spread genetic testing will be a shift from private group insurance to national health insurance. The reason is that as the cost of acquiring and using genetic information decrease and the costs of covering people with late on-set genetic diseases increase, there will be adverse selection. On the one hand, people free from such

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disorders will have an ever increasing incentive to shift from community rating to individual risk coverage at lower prices, while those at greater genetic risk seek the best group health care coverage. The outcome of such full-scale adverse selection will be the bankruptcy of private group health insurance plans and the establishment of nationalized health insurance in which all medical costs are met through progressive taxation. Whether this will take the form of a British NHS style system, a single payer Canadian system, or some other, is another question.

If I am correct about health insurance, in the medium term and the long run the risk of losing it provides no prudential or moral argument for privacy of genetic information. If anything, privacy will destroy private individual and group health insurance.

The solution to the problem of misusing genetic data in health insurance is not safeguards against disclosure of information. It is a national health insurance system. Similarly, there are well-known and well-trodden ways of mitigating the impact of employment discrimination based on genetic information. We need only reduce the transaction costs to individuals of winning law suits against employment discriminators. As for the problem of social stigma, one need only reflect on how mores about inter-racial marriage, sexual orientation, public nudity, or for that matter Downs-syndrome have changed as a result of openness to see that the social stigma associated with a genetic disease is likely to be much reduced over time, and in fact to be reduced as a result of making information public, not keeping it private.

Once the costs of disclosing genetic information have been reduced, arguments in favor of keeping it private will also be much reduced in their force. Indeed, I believe that arguments against privacy of genetic information will become stronger, and so strong that we need to consider how to deal with the obstacles to welfare (individual and general) which an atavistic demand for needless privacy

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raises. Privacy turns out to be the problem, not the solution.

To see the problem consider the work of Decode Genetics, a company which has signed an agreement with the government of Iceland to collect and analyze genetic data, medical records, and genealogical information about the people of Iceland, in order to undertake commercially and therapeutically valuable research on disease incidence, genetic correlations of morbidity/mortality and longevity, drug effectiveness and interaction effects, in the design of health care delivery. Decode has already claimed some important discoveries and entered into subsequent contracts with Roche, the parent company of Genentech, to develop new genetically based treatments. Decode and the Icelandic government have recognized that there is a potential for very great benefits in health care to be derived at relatively low cost from aggregating information which is individually of little value. However bioethicists have complained that Decode's deal with the Icelandic government is morally unacceptable for at least two reasons: it does not fully respect patient autonomy because it allows for an opt-out privacy request instead of a positive act of informed consent to the waiver of privacy by participants, and because it "commodifies" information in a way which these bioethicists deem to be dehumanizing. These may be serious concerns, but their seriousness is sure to be reduced at least a little as the potential increases for direct benefits to the individuals who waive their rights to privacy. And they will increase in two ways: first, each Icelandic participant will benefit from improvements in Icelandic health care made possible by mining Decode's data; second each Icelandic citizen will profit from the monetary returns to the Icelandic government from the sale to non-Icelanders of this aggregate information and/or products it helps produce.

Notice that the Decode deal with the Icelandic government allows any Icelander to free ride on these benefits. If one or another Icelander opts out and refuses to provide genetic data, the impact on

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the value to each of these opters-out of Decode's product will remain the same, and they will incur no loss from the disclosure of their information . (Never mind the fact that an excellent national health care scheme and other special features of the culture and economy of Iceland make the individual's costs of disclosure slight.) But if each potential participant reasons this way, then of course there will be no aggregated data to mine and no individual benefit. The situation is one economists call a Prisoner's dilemma: Each Icelander would be best off if all Icelanders but he shared their genetic information with Decode. Each would be worst off if only he disclosed genetic information to Decode and no one else did. The second best solution is for all to disclose to Decode and all reap the benefit, and the third best is all keep their information private and secure no improvement in their health. The problem is that individual self-interest leads all Icelanders to the third best solution—don't disclose: if no one else does, you're a sucker to do so, and if others do, you can free-ride by not disclosing. Only some further inducements to individual disclosure can shift everyone from the third best to the second best outcome, in which all disclose and all profit from the gains of Decode.

We may speculate on how Decode has managed to secure 92 % disclosure of genetic information by the citizens of Iceland. But the take home lesson is obvious. Unless we are prepared to allow a private company and the citizens of another country to profit by surrendering their genetic information and selling it to us, we need to rethink our own attitudes towards genetic privacy. Of course if you consider that Decode's deal with the Icelandic government is morally questionable, you may not wish to purchase the improved health care it results in. But if you are prepared to do so, you should be prepared to contemplate arrangements in our own and other countries that allow for the same surrender of genetic privacy in order to secure enhanced health for all. Moreover, we already know that the Icelandic data will be of limited use for people from non-Northern European ethnic groups, and this

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majority of the population will be deprived of the same amount of benefit as the White Anglo Saxon population. So, even if we could buy genetic information from Decode, it would not be as beneficial to us as our own data would be.

Some may reply that the gains from mining large quantities of genetic data are too speculative to trade for the loss of privacy required. But first, recall, the trade off we are considering is to be weighed against the background of a national health insurance scheme, strong deterrence against employment discrimination and an effective program of consciousness raising about genetic endowments. Second, to see how great can be the potential returns to each of us of the abolition of privacy in genetic information, consider an arena of human endeavor in which strictures against privacy are very strong, and what the result of those strictures has been. As sociologists have recognized since Robert K. Merton, the ruling informational-ethic in pure scientific research is “communism”—the holding of all property in common. In scientific research there is no such thing as private property when it comes to data, or even theory. There is, among pure research scientists, a special duty to publish data as soon as it has been analyzed. The reward system of science is structured to enforce this communism. The highest prestige and the best opportunities to do more research are accorded to those with priority in disclosure—ie. immortality as the discover; scientists who keep their data secret are often stigmatized and sanctioned. Over the last 400 years the result has been a continuing flow of completely unpredicted net enhancements of human welfare. The system works because it enforces communism about information and has “convinced” participants to accept non-monetary payment—scientific prestige—for the information they have freely surrendered to the scientific community. Had scientists demanded monetary payment for disclosure, we can be sure that both science and human welfare would not have advanced as far as in fact communism about information has made possible.

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If the comparison to science is apt, then the benefits to communism about information will be both huge and completely unpredictable in any detail. And either we will never know what they are until we convince a sufficiently large number of people to accept this ethic, or else we will find out what some of them are from Decode et. al. and pay for the right to use the information. Are we better off foregoing privacy and mining our own genetic data? I think in the long run and under the conditions stipulated above, the answer is yes.

But this raises the question of how we can get everyone to disclose individual genetic data. Can we permissibly or effectively enforce the disclosure of genetic information? Probably not. Even if we decide that individual autonomy does not trump individual and general welfare, so that coercion is permissible, it is hard to imagine an effective non-totalitarian enforcement scheme, one that people could not circumvent. All that information, no matter how valuable, isn't worth having a police state. The alternative is to convince a large enough number of people to voluntarily disclose their genetic information. We cannot do this by offering to exchange the opportunity to benefit from this data for the waiver of privacy. For once the benefits become great this would turn our strategy of convincing people into a coercive one with punishes non-disclosers with deprivation of the benefits. It is unlikely that we can secure disclosure merely by promulgating the philosophically well-grounded claim that biological information is not the property of the person it is about, and so that person has no property rights over it. It is doubtful that anything like this will be enough to convince people otherwise leery to disclose their genetic information to do so. On the other hand, who knows, perhaps most people as less concerned about this matter than those who have advocated the establishment of ever stronger privacy protections as the ease of violation becomes cheaper and more tempting. If they are not, then like the proverbial pot of gold at the end of the rainbow, the full benefits of genomics will ever be out of reach for all but the

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enlightened citizens of Iceland.

## Conclusion

I have focused on three serious medium term problems raised by the revolution in genomics. Unlike almost all of the short term problems raised by genomics, these problems are ones for which currently available solutions do not seem to provide adequate models. Of course they are not completely novel problems: each involves the eternal conflict between individual rights and general welfare, between what the bioethicists call autonomy and beneficence. In the past these conflicts have almost always been decided in favor of autonomy. But what genomics does is raise the stakes for individual and collective human welfare. The improvement in genetic endowments it promises is so great that individuals will certainly exploit current commitments to personal autonomy in their attempt to secure these benefits for themselves no matter how great the cost for the community. This raises the first problem of child design markets I addressed.. On the other hand, the prospects for improved collective welfare, especially in the less developed world, are so great that the temptation to kill the goose that lays the golden eggs becomes morally inescapable. This is my second problem. It is a problem of designing what the economists call “incentive compatible” mechanisms. The failure to solve it is nothing short of the failure which led to the collapse of the Soviet Union. If the Soviet planners couldn’t produce scientific and technological innovation with coercion on a totalitarian scale, it is hard to see how the international community could do so without any coercive powers. Like the second problem, the third problem of encouraging openness about individual genetic data shows that a widely and strongly held moral intuition about the respect for personal privacy of autonomous agents promises to be a grave impediment to enhancing these very agents’ and other people’s welfare in the medium and the long term.

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Unlike the short term problems of genomics, these problems will call for the most serious efforts to rethink and redesign the institutions that regulate human affairs.

Alex Rosenberg

Duke University

Are these long term problems...before we are all dead, but several generations from now? I.e. will they be overtaken by events?

Child design swamped by adult design? Market in child design expands into a market for adult self design...This will make matters worse unless the costs decline... then what will we have? People actualizing their potentials to be similar!

Logic of Discovery? When making treatments becomes algorithmic, the problem of intellectual property rights will disappear.

Health data will become innocuous? Enough genetic technology will reduce health care costs immensely, because of somatic gene therapy, and completely effective pharmaceuticals.

So the last two problems go away, leaving the first one even more troublesome?

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Long term problems: depopulation, as people become very long-lived and cloning becomes means of reproduction.