
IMPACT EVALUATION: BIOTECHNOLOGY, HEALTHCARE, AND RESPONSIBILITY

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PREFACE

Genetics, bioinformatics, and healthcare are very serious and complicated issues. This paper should not be interpreted to be that of an informed party or even that of an author with a considerable understanding of the material in question. It should not be critiqued as a scientific analysis or as a policy recommendation, as it is neither. The author willingly concedes considerable ignorance in the complex scientific details and the titanic policy implications of the issue and writes solely with the purpose of sharing some thoughts on the issues at hand. Furthermore, considering the limited space and time in light of the tremendously complex issue, the ideas cannot be fully expressed and will beg forgiveness for an argument that is in many ways incomplete.

INTRODUCTION

With the completion of the genome sequencing, and the success of the human genome mapping effort, society is now faced with the many questions concerning the enormous impact of this new genetic information. Already, individuals and families are finding hope and encouragement in the potential promises of genetics for diagnosis, treatment, and improved health. There is no doubt that this burgeoning science is moving quickly and is poised to be one of the most significant discoveries in the history of biosciences and perhaps of humanity itself. However, this technology is advancing at such a pace that the greater public has little hope of keeping informed and lacks the ability to understand its impact in regards to both its potential benefits its looming risks. Because of this ignorance, the public's fear of the undeniable moral, ethical, social, and economic implications are often misplaced and threaten the realization of the discovery's full potential. As the effort moves forward, we must address these issues in an intelligent and informed fashion, placing responsibility where it lies and proceeding with a dedication to society's most basic responsibilities.

THE PREMISE

In continuation, it is imperative that an outline of the operatives behind any further suggestions or issues taken be clearly established. First, operating on the idea that it is every society's primary responsibility to guard the interests of its members while seeking the greatest in health and happiness for each. Secondly, that access to health care, education, and employment is essential to all individuals regardless of race, gender, creed, or genetic inheritance. The argument operates within this basic framework where the potential for genetic information to advance the general condition of health in the world is unquestionable. However, it also recognizes that these benefits come with serious risks threatening access health care, education, and employment and thereby the happiness of certain

individuals. This paper offers an opinion on these concerns and possible directions for mediation, specifically in terms of discrimination and healthcare.

RISK OF EMPLOYMENT DISCRIMINATION

Considering the history of employment discrimination, it is easy to understand why this issue is at the forefront of the debate. Such advances have been made in the past, focusing the selection of employees on their talents, merits, and contributions. In terms of employment, where gender, race, or age make no difference in one's ability to perform a task, so should such an application be made of genetic information. There is no genetic information that could be rendered by a test that would immediately impair an individual's current ability or merit no more so than would a pregnancy or the oncoming of old age. Therefore, access to genetic information constitutes a serious breach of personal privacy and is an obvious violation of the constitutional intention for fair employment. There are some exceptions, where access to the information would aide the employer in selected a "better" employee. For example, in companies where working conditions restrict those who are known to have asthma, there would seem to be a potential benefit in knowing genetic information. This application is ill placed and the efforts should instead be focused on ridding the environment of the condition causing asthmatic responses. In the interests of protecting fair access to employment, genetic information should immediately be included in the list of properties against which an employer may not discriminate.

RISK OF INSURANCE DISCRIMINATION

Notice that insurance and employment discrimination were not simply grouped together under a heading of genetic discrimination. Genetics and the possible health benefits contained within the application of genetic science are not the business of employers and an unfair relation between the two must be prohibited, just as is an unfair relationship between race and employment. However, health in

all forms is very much the business of insurance, specifically health insurers – those in question here. You simply cannot separate the implication of genetic information from insurance in the same way you can in regards to employment.

Why is insurance such a large concern? The answer is rather simple. Genetics as a science and its applications in diagnosis or treatment are expensive. Any application of this technology involves considerable cost. And when dealing in questions of money, people take serious notice and maintain some very strong opinions. The idea that genetic information could render someone without insurance, thereby making him or her personally financially responsible for its application is terrifying. A large amount of angst, criticism, and even regulation has befallen the insurance industry in this regard. This response is misdirected, for it is not the insurance industry that is in question here. To understand the argument, one must understand the concept of health insurance and its operation.

THE HEALTH INSURANCE INDUSTRY¹

Insurance, defined: “Coverage by a contract binding a party to indemnify another against specified loss in return for premiums paid.” The logic of this basic definition works on the level of the individual, the level at which most of the argument surrounding insurance lies. Insurance for the individual is security, where the individual would ideally receive treatment without paying the full price for it. This works on the individual level because there are others who will pay much more for insurance than will be paid on their behalf for their healthcare. This careful balance, where some pay more than they receive and other receive more than they pay, is the basis on which the insurance industry operates. To maintain this balance, a careful system of premiums – the price an individual must pay to receive coverage by the insurer – are calculated for each individual purchasing healthcare². For this system to

¹ This applies specifically to health insurances and does not deal with life or other types of insurance.

² For simplicity, only individual plans are discussed, but the same reasoning applies to group plans

work, the premiums must be actuarially fair. This is to say that it is impossible for the insurance company to receive less in premiums than it would pay out for health expenses. To achieve actuary fairness, an insurer must assess the risk of insuring an individual and thereby calculate the likelihood of having to cover expenses on their behalf. Then, the insurer would charge a premium equal to the expected payout. In the event a large number of the insured suffer misfortunes and claim against their policies relative to the number of insured who do not suffer misfortunes and do not claim against their policy, the careful balance is upset and the insurer will raise premiums to cover the additional payout. Most people do not understand this idea; or rather simply do not like it. Insurance is often seen as a way to get something without paying for it, at least in the case where one's claims are greater than one's premiums. It is important to understand that insurance companies do not make a profit from the business of insurance. Free market competitive forces prevent the insurance companies from charging a premium for a coverage plan greater than the likely payout against that plan. Insurance companies do make a profit however, but this profit comes from the business of investment, not from the underwriting of insurance³. In the period between the receipt of a premium and the payout against it, an insurer invests that premium at a rate greater than the individual could or would. The profit from insurance is made on the investment of the premiums (the "float") in this intermediary period.

Anti-selection. Premium prices are based on the theory that the insurer knows as much about the applicant's risk/chance of illness as does the applicant and can thereby price an actuarially fair premium. However, sometimes the applicant knows more about his or her risk than does the insurer. For example this occurs when an applicant indicates to the insurer that he is a non-smoker, when in fact, he is a smoker. This gives the insurer an inaccurate indication of the applicant's health condition and results in a lower premium when the added health risks of smoking would obviously increase the persons

³ Obviously this applies in theory. Niche insurers and group policies have created a window for profit from premiums that are above the actuarially fair price.

expected claim against the policy. In this case, insurance becomes a bargain for those with greater risk, and an unfair burden for those with lower risk. Also in this case, the insurer has not properly priced policies, upsetting the balance between premiums and payout, and will therefore have to increase premiums for each of the insured. This occurrence is called anti-selection

GENETIC INFORMATION AND HEALTH INSURANCE

Why does the advent of genetic information affect the insurance industry? The assessment of risk, and thereby the pricing of premiums is based on the idea that insurers can render some assessment of risk from both previous and current health indicators including physical exams, medical records, family related ailments, frequency of illness, and previous claims. Insurance is a game of risk to cover chance in the game of life. But it is only to cover chance - those incidents or accidents that are not predictable and that come without previous knowledge where financial planning could not be expected. For if an ailment is a predictable result of some previous indication, or the realization of some afore known inevitability, it does not come about by chance. If you remove the element of chance from the game of life, you remove the element of risk from the game of insurance, and since insurance is based on risk alone, you defy the very nature of insurance. It is for this reason that insurers will not cover pre-existing conditions – that is, conditions of known existence before entering into the policy where the ailment does not come about by chance. The issue at question is essentially whether or not genetic information is a pre-existing condition. For example, if an individual were to have full knowledge, resulting from genetic testing, that he or she carried the genetic code for multiple sclerosis⁴, its manifestation would not be that of chance. The knowledge of its existence must be included for the insurer to calculate a premium such that it equals the expected payout. Concealing its existence from the

⁴ A chronic degenerative disease of the central nervous system in which gradual destruction of myelin occurs in patches throughout the brain or spinal cord or both, interfering with the nerve pathways and causing muscular weakness, loss of coordination, and speech and visual disturbances. It occurs chiefly in young adults and is thought to be caused by a defect in the immune system that may be of genetic or viral origin.

insurer disturbs the industry equilibrium. Since someone must pay for the treatment, the insurance company will spread the cost by increasing the premiums of the others insured. So what exactly is the problem with this? The costs then go to unsuspecting and unknowing consumers who have been honest in portraying an accurate picture of their health condition and pay a premium accordingly. To protect consumers from this very process, the Medical Information Bureau (“MIB”) was created “to protect the honest consumers against higher premiums which would be necessary if the forgetful or dishonest applicants were too often successful.” By collecting information about each applicant from all available resources, the MIB assists the insurance firms in assessing the accuracy of an application for coverage. If an individual's genetic information, and thereby a list of all ailments carried by that individual, were to exist by lieu of a genetic test, should it be available to the MIB and the insurance industry? Yes, and it must be to preserve the insurance industry so that it may continue to do exactly what it was intended – to cover chance, those incidents or accidents that are not predictable and that come without previous knowledge where financial planning could not be expected. It is unfair to the insurance industry and to other consumers to conceal information about your health condition.

RESPONSIBILITY

At the point where insurers have access to genetic information and are allowed to *fairly* discriminate, two new problems arise. First, many people who are ill or will become ill with a genetic condition will be denied health insurance. Secondly, people will refuse to have genetic testing for fear of discrimination, hampering the advancement of the science and its potential benefits.

As mentioned before in the framework, it is essential that a society provide for access to healthcare. This would seem to be in direct conflict with advocating the rights of insurance firms to decline coverage to individuals on the basis of genetic information. This is not a contradiction. Instead, it is a call for the proper redirection of responsibility. It is not the responsibility of the insurance

industry to pay for the expensive techniques developed for genetic testing, diagnosis, or treatment. Nor is it the responsibility of honest consumers of insurance to pay for the concealed ailments of those who dishonestly abuse the insurance industry and the very nature of insurance itself. This begs the real question, “Who is responsible for your genetic information?”

YOU ARE! Like in every other instance in life, ultimately, you are responsible for yourself. Genetic information is no different, it is a part of who you are whether it is unfortunate or not. You can certainly not make someone else responsible for your genetic information. Perhaps this can be made clearer by identifying a parallel with its opposite. Just as some people may inherit genes that cause illness, so do some people inherit genes that make them more handsome, more appealing with desirable eye color and height giving an obvious advantage in beauty. Or perhaps someone inherits an outstanding physical ability, like that of excessive speed, agility, or skill that enables that person to pursue a career as a professional athlete. There is also significant evidence to suggest that intelligence is largely inherited. Should a genetic trait give a desirable characteristic, the individual would most certainly take responsibility for his genetics and would not likely be willing to share those benefits with the rest of society. Is it reasonable to reverse the scenario, now with undesirable genetic traits and refuse responsibly?

Lets also consider an alternative scenario in terms of health insurance. For example, consider the case where the genetic information indicates that instead of illness or ailment, the individual is of perfect genetic makeup and will not be as likely to fall to illness. The insurance industry, knowing the chance of ailment (say near zero), would price their risk of payment accordingly (near zero). Is it likely that individual would be willing to share this result with his fellow policy holders, lowering everyone’s

premium, or would he simply argue that the fortune of his genetic makeup should fall solely on himself, and enjoy a \$0⁵ insurance premium?

Just as an individual alone can reap the benefits of his or her genetic makeup, so must that individual alone take responsibility for his or her genetic makeup, however unfortunate it may be.

HEALTHCARE

“Biotechnology will change the relationship between the existing components of the American healthcare value chain and create new and formidable social and economic pressures,” so said Doug Kalish, professor at the Hass School of Business at the University of California at Berkeley. In this assessment, it will not only change the relationship between the existing components, but change the components themselves. The formidable social and economic pressures he mentions should be addressed in a clear and focused manner, even if it involves a complete revolution of the system. It is simply not possible to work within an old frame and within the boundaries of an old system when you are defying the very foundation of that system in doing so. Responsibility must be accepted wherever it may lie and not be misdirected to an easy and obvious target.

As mentioned before, giving insurance firms access to genetic information and allowing discrimination in that regard would essentially leave those misfortunate souls without insurance. Yes, exactly, they don't need insurance – protection from the unexpected – they need healthcare and that's a different issue. Healthcare, not insurance is what we must provide access to regardless of genetic information. Where the individual is not capable of personally financing testing, diagnosis, or treatment, then let it be the responsibility of society, perhaps in the form of a new agency or a redesigned old one (Medicaid?) dispensing nationally collected revenues for this expense if society does indeed deem it a

⁵ An obvious exaggeration as the premium would be priced in accordance with the risk of chance illness, which would most definitely be higher than \$0.

national necessity. But do not attempt to finance the support of the unfortunate in the form of unfairly high premiums on those honest paying insurance consumers. Redesign the healthcare system, the tax system, the welfare or Medicaid system, but focus efforts where they belong.

SCIENTIFIC ADVANCEMENT

There were two problems that arose as a result of disclosing genetic information to insurers. Now that responsibility has been properly directed and action properly focused, the second issue becomes one of non-import. Fear of genetic discrimination should not be a stumbling block for the advancement of genetic technology, nor a hindrance in the health of a nation. Once individuals accept responsibility for their own genetic information and once a society makes a conscious dedication to healthcare, the fear too can be properly directed and in this way, it will not fall on the science itself. Removing an individual's fear of unfair discrimination of employment, and ensuring proper medical care to every member of a society, will ultimately allow the science to progress and humanity to reap the full benefit of its discovery.

CONCLUSION

It is quite normal to be afraid of what we do not know or what we do not understand. However, it is not acceptable to allow this fear to prevent our progress. We must become informed of the issues and focus our efforts at dealing with those concerns. We must not shirk our responsibilities nor throw them off unwarranted. In this way, we must take active steps to prevent employment discrimination as a result of genetic testing or newly available genetic information. We must realize the misplaced focus on the insurance industry as a financier of the technology. If we are to remain dedicated to universal health care, that system must be changed. As the effort moves forward, we must address these issues in an

intelligent and informed fashion, placing responsibility where it lies and proceeding with a dedication to society's most basic responsibilities.

BIBLIOGRAPHY:

- *Genetic Discrimination in Health Insurance & Employment Act*. Genetic Alliance, June 2000
- *Insurance and the New Genetics: Test results may threaten patients' coverage*. Genetic Medicine. www.hhmi.org/genmed/insure.htm
- *Should Insurance Pay for Preventive Services Suggested By Genetics?* Jean Lawrence, Managed Care. Jan 1997. www.managedcaremag.com/archives/9701/9701_genetics.shtml
- *Genetic Data 'insurance fear'*. Wellcome Trust and the Medical Research Council. BBC News. Nov 2000. <http://news.bbc.co.uk/1/hi/health/1038801.stm>
- *"Panel discusses genetics impact on insurance"*. MIT Tech Talk. MIT NEWS OFFICE, Nov 1994
- *Whose hands on your genes?* Faculty and Institute of Actuaries. March 2001 www.actuaries.org/uk/genetics/genes.html
- *The Impact of Biotechnology on the US Healthcare System*. Douglas Kalish, Geoffrey Thompson, Haas School of Business, University of California at Berkeley