The Use of Genetic Testing Information in the Insurance Industry: An Ethical and Societal Analysis of Public Policy Options

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Abstract
Informed by a search of the literature about the usage of genetic testing information (GTI) by insurance companies, this paper presents a practical ethical analysis of several distinct public policy options that might be used to govern or constrain GTI usage by insurance providers. As medical research advances and the extension to the Human Genome Project (2016) moves to its fullness over the next decade, such research efforts will allow the full synthesis of human DNA to be connected to predictive health dispositions. As testing costs fall, there will be ever more pressure for citizens to disclose GTI. Genetic testing information is integral to future medical care because it can be used to better assess individually tailored medical therapies as well as to allow a more informed risk analysis by the insurance industry, which in some countries such as the USA, underwrites a majority of citizen medical expenses. As discussed in this examination, the revelation of people’s uniquely personal GTI to insurers has enormous societal implications. The major contribution of the paper is to offer policy makers and concerned citizens a nuanced articulation of the basic options to regulate GTI, with a special consideration for ethical fairness and equity. As genetic based medicine blossoms and pressures to reduce healthcare costs increase, there will be an ever greater impetus for countries to revisit their genetic testing policies. Organizations and policy makers striving to create GTI oversights perceived to be both “fair” and “effective” need to be aware of the ethical perspectives discussed in this paper.

Keywords: Genetic Testing, Health Insurance, Healthcare Ethics, Discrimination, Applied Ethics, Distributive Justice, Health Information Privacy
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“The commitment to equality embodied in our political tradition...is an assertion that before this government, this system of laws and courts, all persons are to be given equal standing, and all persons must be treated with equal regard. Human genetics, in contrast, is a science of inequality—a study of human particularity and differences.”

Thomas H. Murray (1992, 12)

Introduction

In a now famous June 2000 Press Conference, U.S. President Bill Clinton announced that because of the progress that has been made in deciphering the code of life, our children’s children will probably know the word “cancer” only as a constellation of stars. The President’s comments reflect the optimistic zeitgeist of the ending 20th century and the great expectations that many people had about future gene technology. However, those hopes for fundamental transformation of medical practice by genetic technology were also accompanied by fears. Some critics believed that genetic information, which has been hailed as a colossal milestone in the history of science, might be used in ways that are detrimental to humanity (Fukuyama 2002). Another fear, which was partially based on the dreadful history of eugenics (Buchanan et al. 2000; Roberts 2010; Vaughn Switzer 2003), was the prediction that gene technology will result in new forms of genetic discrimination: “the idea that human genomics would lead to the emergence of a social underclass of carriers of bad genes” (Zwart 2015, 316). Finally, there is the alarming expectation that genetic testing might lead to a detrimental change in the very
purpose of health insurance; that is, a change from insurance against all risks to “insurance only for the risk free” (Harris 1992, 221; Hedgecoe 1996).

More than a decade after the completion of the original Human Genome Project in 2003 – along with a three-billion-dollar international collaborative effort to sequence the entirety of the human hereditary information - it seems that some of the hopes as well as fears about genetic mapping were overrated. Indeed, thus far, the consequences of gene technology for health care, medicine, and human daily existence in general have been modest (Zwart 2015). Further, contrary to expectations, genetic testing has not yet altered the very concept of health insurance. Documented instances of genetic discrimination have been quite limited so far (Roberts 2010). However, the current lack of discrimination might be less due to the innocuous nature of the new technology and more attributable to the high cost of genetic sequencing that currently renders it impracticable for widespread commercial applications. In addition, many developed countries preemptively introduced anti-genetic discrimination laws and regulations (Joly et al. 2010; Otlowski et al. 2012). But expected medical advances in the coming years of the 21st Century will place renewed pressure for widespread genetic testing and the sharing of GTI results with all the healthcare community.

While progressing more slowly than originally expected, gene technology is constantly improving. At present, genetic testing is already available for more than 2000 conditions (NIH 2016). Most tests look at single genes and are typically used to diagnose rare genetic disorders. However, increasingly, a number of tests are being developed to look at multiple genes that may increase or decrease a person’s probability of coming down with common diseases, such as cancer or diabetes. Such tests will likely lead to more effective ‘personalized care’ with the potential to help prevent common diseases and/or guide treatment or intervention options (CDC
Importantly, the cost of genetic testing will continue to decline. Eventually the price of the ultimate genetic test - sequencing an individual’s entire genome - will be less than $1,000 (NIH 2016).

The decreasing cost and increasing application of genetic testing information (GTI) is not only spurring medical advances but also is sparking the interest of insurance companies to develop more accurate customer risk classifications. Given GTI’s growing relevance, there is still little dialogue in peer reviewed business journals about public policy options for dealing with the use of genetic testing information in the insurance industry. To this end, we investigate feasible and existing public policy choices regulating the use of GTI in the insurance industry from an ethical and societal perspective. Thus, the specific contribution of this literature-informed commentary is to (a) provide an overview of possible genetic discrimination in the insurance industry, (b) evaluate five likely public policy approaches from both an ethical and societal perspective, and finally (c) offer some considerations for policymakers to better mitigate potential GTI discrimination by insurance providers.

A second closely related goal of this exposition is to take on the question of GTI from the standpoint of applied ethics (Singer 1986). Applied ethics is not about constructing new moral theories but rather about using moral philosophy to engage pressing problems of urgency to society, business, medicine, education or other social sectors (Callahan 1990). If done well, such discussions will shed insight on important issues of proximate concern (i.e. the use and misuse of genetic testing information by insurers in this instance). In the final analysis, business ethics is about what managers should do concerning the action options that they face (Walton 1988).
Risk Classification and Genetic Discrimination in the Insurance Industry

The purpose of insurance is that individuals gather resources against risk by building risk pools. Policyholders pay into the pool via premiums and get money out of the pool if they suffer losses by adverse events such as unforeseen poor health or accidents (Landes 2015). Insurance companies have an incentive to distinguish between policyholders that pose different risks (probabilities of payout) in order to develop subgroups of policyholders with similar expected cost for the company. Policyholders in one subgroup pay the same premium and share in any realized losses due to unforeseen events (fire with home insurance, health issues with health insurance etc.). For example, fire insurance is more expensive for homes built of wood than brick; smokers pay a higher premium for health insurance etc. This process is called risk classification. “Risk classification refers to the use of observable characteristics such as gender, race, behavior, or the outcome of genetic tests to price or structure insurance policies.” (Dionne and Rothschild 2014, 184). In general, in settings with a market-based insurance provision, risk classification is associated with lower cost (Crocker and Snow 2013), lower information asymmetry, and higher efficiency (Dionne and Rothschild 2014).

Genetic testing information (GTI) can help insurance companies to better predict the risk of individual applicants. This in turn allows the insurer to develop a more accurate and economically efficient risk classification system for the insured (Brockett and Tankersley 1997). The more accurate the risk classification, the more closely the premium charged to a policyholder reflects her actual expected losses. That is, a more accurate risk classification scheme, using genetic information, leads to a more equitable distribution of loss costs. However, a more equitable distribution does not necessarily lead to the most desirable outcome from an ethical or societal perspective. For example, as discussed later, the results of a genetic test might
make some people practically uninsurable. The ensuing financial and human burden for those individuals might be equitable from a commercial standard but is still unacceptable from a societal perspective.

It is also worth noting that in the economic literature, the general principle of risk classification, which is associated with benefits for the insurer and insured alike, is fairly uncontroversial (Crocker and Snow 2013; Dionne and Rothschild 2014). It is the classification based on certain variables that is controversial. For example, it is commonly accepted that car insurers place drivers in different risk classes based on their past driving record but it is much more controversial if health insurers develop risk classes based on genetic information.

Also, in an insurance industry setting, “classification” and “discrimination” are expressions often used interchangeably. Arguably, in this context, discrimination in itself is not necessarily bad (or doesn't refer to an action or a situation that is necessarily objectionable). Therefore, an ethical analysis is required to determine whether and to which degree genetic discrimination – risk classification based on genetic information - is objectionable as well as a moral assessment of the laws and regulations designed to constrain the usage of GTI by the insurance industry. Given that the health insurance industry in the US alone, based on revenues, is a one-half trillion dollar industry, such discussions are also an economic imperative (Deloitte, 2013).

**Ethical Frameworks**

While moral positions can be clarified by particular ethical frameworks, justifying the particular ethical frameworks used in a particular analysis is much more complex and, ultimately, not devoid of subjectivity (Nill et al. 2015). Applying multiple ethical frameworks to tough issues—
such as the practice of genetic risk classification--provides for a richer and potentially more objective analysis. The disadvantage is that different ethical frameworks can sometimes lead to different and perhaps even contradicting conclusions (Laczniak and Murpy 1993). In such instances, moral imagination (i.e., prudential discernment and deliberation) is required to reason to a logically defensible resolution (Werhane 2002; Laczniak and Murphy 2006). Our analysis below is based on both teleological and deontological moral philosophies, especially consequentialist utilitarian cost-benefit calculations, Kantian considerations, Rawls’ (1971) “theory of justice as fairness” and Hans Jonas’ (1985; 1979) “imperative of responsibility”.

**Teleology and Deontology**

Teleology and deontology have historically been used for ethical investigations of business issues in the Europe and the U.S. (Nill and Schibrowsky 2007). Indeed, most people use some form of deontological and teleological reasoning in their ethical decision-making process regarding business matters (Ferrell and Gresham 1985; Jones 1991; Forsyth 1992; Barnett et al. 1998). For example, the Hunt and Vitell model, pieces of which have been empirically tested numerous times, posits that an individual’s ethical judgments can be a function of both deontological and teleological evaluation (Hunt and Vitell 1986, 2006; Vitell and Hunt 2015).

One teleological approach, *utilitarianism*, perhaps more accurately labeled a consequentialist theory because it mostly focuses on the outcomes of actions, is an often used approach to assess public policy. According to utilitarianism as introduced by John Stuart Mill (1806-1873) and Jeremy Bentham (1748-1832), one should choose the alternative that leads to the greatest happiness of the greatest number (Mill 1979). Classic utilitarianism has often been criticized for its “massive measurement problems” (Hunt and Vitell 1986, 7), its lack of guiding
values, and its non-specification of the logic path taken to predict outcomes or desired ends. To counter this criticism, some approaches towards utilitarianism, labeled rule utilitarianism, posit that one should choose the rule that promotes the greatest happiness of the greatest number rather than evaluating an action by its consequences only. By including deontological elements (rules), utilitarianism circumvents some of the original criticism (for example, lying would no longer be acceptable even if it leads to the best outcome) but faces other problems (justifying what the rules should be etc.) (Hare 1991; Frankena 1963).

Deontological theories such as Kant’s categorical imperative, the golden rule, and classical virtue ethics judge the value of actions only from the perspective of their inherent wrongness or rightness regardless of the consequences (Nill and Schibrowsky 2007). Thus, deontology relies on the duty to follow absolute principles (Bowie 2002; 1999). For example, Kant (1724-1804) formulated three categorical imperatives of which the first resembles the golden rule: “Act according to that maxim only, which you can wish, at the same time to become a universal law” (Kant 1965, 42). This imperative implies that reciprocity constitutes a universal moral standard among rational beings including the duty to respect and treat every stakeholder as a person. Deontological approaches have mainly been criticized for being too abstract and elusive to provide practical guidance in modern business settings (Nill and Schibrowsky 2007). Furthermore, decisions based on the perception of absolute moral duties, such as categorical imperatives, depend on the sometimes flawed moral reasoning of the person doing the analysis and may offer contradictory conclusions (Murphy et al. 2005).

Rawlsian Justice.
John Rawls (1971) defines “justice as fairness” from a deontological and contractual perspective; he assumes a primacy of individual rights over the greatest good of the greatest number. Rawls' approach to justice is based on a conceptualization of a co-operative social contract that overcomes Hobbes primitive state of nature of “war of all against all” (Ricoeur 1990). “Justice as fairness” begins with the idea of the ‘original position’ which is derived from a thought experiment that imagines a *veil of ignorance*. That is, visualize that one does not know in what position they will end up in a hypothetical society—when the veil is removed, they could be king or pauper. One doesn’t even know their distribution of natural talents and abilities. Hence the bargaining problems which arise in real life—owing to the desire to preserve one’s comparative advantage--are precluded in Rawls’ thought experiment (Schlegelmilch 1998). Under the veil of ignorance, Rawls (1971. 302) posits that rational persons—to protect themselves from very bad outcomes after the veil is removed--will choose two supreme principles that drive the conjectural social system *toward equality*. Because participants don’t know their position in the hypothetical society their logical choice is to opt for an equality producing system. These two supreme principles of justice (Rawls (1971, 302) are:

1. *Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.*

This principle is called the *Liberty Principle* (LP). It is highly consistent with the traditions of many liberal democracies.

2. *Social and economic inequalities are to be arranged so that they are both:*

   *(a) to the greatest benefit of the least advantaged, consistent with the savings principle,*

   *and (b) attached to offices and positions open to all under conditions of fair equality of opportunity*.”
This principle, a more novel one, is called the *Difference Principle* (DP). It basically cautions against new actions, programs or policies that might further disadvantage those persons who are already least well-off. It is this conception of “fairness”, captured in Rawls’ difference principle, which adequately represents our definition of the term as used in the analysis below. Thus, expanded usage of genetic testing information (GTI) could be detrimental to some of the most vulnerable persons (i.e., those projected to be sickest) from the standpoint of Rawlsian fairness.

Similar to the criticism of deontological duties, Rawls’ approach also depends on the (sometimes inaccurate) moral reasoning of persons doing the analysis. And obviously, actually measuring the ‘most extensive liberty’ possible and ‘benefit to the least advantaged’ is a tremendously difficult task.

**Jonasian Responsibility**

Hans Jonas’ (1985; 1979) *imperative of responsibility*, which is influential in the environmental movement of several European countries, provides another potential way to morally analyze public policy decisions concerning the use of genetic information in the insurance industry. Jonas recognized that traditional ethical philosophies do not account for the far reaching technological advances that began influencing society in the mid-20th century. In earlier times, technology was simply not powerful enough to threaten the health or survival of large groups of people. For example, there was minimal need to morally consider the impact of emergent technology on people living in regions far away from one another or upon future generations. However modern technology, including GTI, has the potential to severely influence the well-being of many generations to come. Jonas, who was especially influenced by the threat of nuclear warfare, maintained that – if we don’t use our technology responsibly - it is imaginable that mankind as
we know it might not survive. Jonas argues that since it is impossible to predict with any degree of accuracy the outcomes and consequences of new technology, it is prudent to assume a ‘in dubio pro malo’ (“when in doubt, assume the worse alternative”) position (Jonas 1987). The ‘in dubio pro malo’ principle only makes sense if potentially lethal consequences for mankind are in play. Thus, the main objective of Jonas’ imperative of responsibility is to avoid the most catastrophic outcomes for mankind. Imitating Kant’s categorical imperative, Jonas formulates his imperative of responsibility as follows:

“Act to that maxim so that the effects of your actions are compatible with the permanence of genuine human life”

Jonas (1994) emphasizes that his ethical theory is not meant to replace traditional approaches. It is meant to supplement existing ethical theory specifically in those cases where new technologies might threaten the survival of humankind as we know it. Accordingly, Jonas (1994) refers to his imperative of responsibility as ‘Vermeidungsethik’ (ethical approach of avoidance), indicating that the most severe threats to humanity are to be avoided, even if the probability of those threats becoming reality is very low. Not surprisingly, since Jonas is concerned with possible future consequences of present decisions about technology upon persons, he is also very protective of personal rights, as we shall see in his “right not to know” corollary discussed below (Jonas 1987).

Jonas’ ethical approach has been criticized for being somewhat elusive about the meaning of ‘the permanence of genuine human life’ (Werner 2003; Birnbacher 1983). Similarly, the imperative of responsibility may not provide abundantly clear guidance about recognizing situations that truly fall under its dominion (Werner 2003; Apel 1988). For example, society does not know with certainty the potential dangers of genetically modified food. There is no
consensus about a worst case scenario. Would it be justified to ban genetically modified food out of fear that we don’t know its potential negative consequences (i.e., applying the ‘in dubio pro malo’ principle) even as the technology already provides many advantages? What is clearer is that many feel that the use of genetic testing information (GTI) by organizations such as insurance companies could be an issue that merits consideration of the great caution that Jonas counsels for simply because our genetic make-up can be so deterministic (Rochman 2017).

**Ethical Analysis of Public Policy Options for the Use of GTI in the Insurance Industry**

The lower cost and higher availability of genetic tests has made the use of GTI for underwriting and pricing of health insurance more cost efficient for insurance companies. Various countries including most European, North American, and a few Asian countries use a variety of different laws, regulations, and other methods to guide how GTI should be used (Otlowski et al. 2012; Joly et al. 2010). Of course, different policy choices will lead to different societal outcomes. In the following sections, we discuss some major policy choices that are (or might be) used to regulate the use of GTI in the insurance industry from an ethical as well as societal perspective. Therefore, a major contribution of this analytical exercise in moral reasoning is to provide an ethical underpinning, using especially utilitarianism, Kantian analysis and the thinking of philosophers Rawls (1971) and Jonas (1994; 1979), to underscore the fairness and efficacy of public policy options that have (or could be) selected to constrain or regulate the use of GTI by health insurers.

The five public policy options – some of which are chosen by different countries (Joly et al. 2010; Otlowski et al. 2012) - discussed here to oversee the use of genetic test information (GTI) by the insurance industry are:
(#1) **Full information ban** on GTI;

(#2) **No restrictions** on GTI use;

(#3) **Limited voluntary disclosure (LVD)** about GTI—with this option, companies cannot require policy holders to get tested, or reveal genetic information, or even know the fact that they did get tested, however, policy holders/applicants are free to disclose their genetic information to the insurer if they decide to get tested and perceive disclosure to be to their advantage;

(#4) **Codes of Conduct** regulating GTI—this option requires policy holders to always disclose if they have taken a genetic test but insurers cannot demand the results of the test;

(#5) **Duty to Disclose (DtD)** GTI—with this option, policy holders have a choice whether they want to get a genetic test or not. Insurance companies cannot require individuals to get tested. However, insurance companies can require individuals that did get tested to disclose the results.

The discussion of the first two options—a full information ban or no restrictions on GTI—are necessarily the longest ethical analyses because these two options represent the polar opposite policy positions on the issue of GTI oversight. The next three options (#3-#5) can be treated far more succinctly because some of the arguments discussed in the first two cases also apply analogously to these hybrid policy options. The main results of our ethical analysis are summarized in Table 1.

1. **Full Information Ban on GTI Use for Risk Classification**

Outright prohibition of requesting and/or using genetic information for underwriting and pricing purposes seems one of the more drastic, and less flexible public policy responses. Under this approach, insurance companies cannot perform a risk classification based on GTI and must offer the same policy with the same premium to everybody. Many countries in Europe (e.g., Austria, Belgium, Denmark, France, Germany, Lithuania, Portugal, and Sweden) have already signed the
Oviedo convention. Signatories to this convention have agreed to adopt legislation that effectively prohibits the use of genetic information for risk classification purposes (Otlowski et al. 2012). While not members of the European Union, Norway and Switzerland also signed the Oviedo convention. England is not a signatory but British insurance companies agreed to a moratorium that effectively prohibits the use of genetic information for underwriting and pricing purposes at least until 2017. Life insurance policies above £500,000 are not part of that moratorium.

In the USA, the Genetic Information Nondiscrimination Act (GINA), which was enacted in 2008, also prohibits health insurers from using GTI for determining eligibility for and pricing of health insurance coverage (Roberts 2010; Harvard Law Review 2009). Health insurers can only request – requiring voluntary consent - genetic testing data for research purposes. They are not allowed to request or require GTI for underwriting purposes. An issuer of health insurance:

“shall not deny or condition the issuance or effectiveness of the policy (including the imposition of any exclusion of benefits under the policy based on a pre-existing condition) and shall not discriminate in the pricing of the policy (including the adjustment of premium rates) of an individual on the basis of the genetic information with respect to such individual” (Genetic Information Nondiscrimination Act of 2008, 2008, page 122 STAT. 899).

Further, health insurers are barred from treating genetic information as a preexisting condition. However, once genetic information has manifested itself into an actual health condition, this condition can no longer be the basis for a GINA discrimination claim (Roberts 2010).
In the following paragraphs, we examine the justification for a full GTI ban from an ethical perspective:

- **Right to privacy.** If insurance companies were allowed to demand and use genetic information for underwriting and pricing purposes, a citizen’s only choice to keep their GTI private would be to forego insurance coverage. In countries with mandatory insurance, citizens might not even have this choice. Either way, an insurance company’s right to request genetic information constitutes a significant intrusion on personal privacy. It is interesting to note that, at least in the U.S., the privacy and confidentiality of other medical information has attracted considerably less attention than in Europe and has been afforded weaker legal protection (Rothstein 1999b).

  From a utilitarian perspective an “information ban” to protect people’s privacy has to be assessed by its consequences - positive and negative - for the society as a whole. As elaborated under the “No Restrictions on GTI” policy below, the use of genetic information might lead to more positive than negative social outcomes (i.e., medical advances, owing to the utilization of GTI, may result in significant improvements for public health and lower costs in the long run). In other words, if “net social happiness”, is or could be achieved through the usage of GTI, a “complete information ban on GTI” option would not be supported with utilitarian calculus.

  From an ethical perspective, a stronger argument in favor of protecting people’s privacy can be made with deontological analysis. Honoring a person’s basic rights is a common deontological moral duty (Dunfee et al. 1999). Arguably, genetic information reveals the core of a person’s identity, the very essence of her physical and mental
makeup. Therefore, the argument goes, the right to keep genetic information private is a basic personal right. This is a perspective suggested by the opening quotation to this article by Murray (1992). Respecting the right to privacy means allowing individual decisions about what information people want to share about their lives. In turn, respecting those basic rights constitutes a moral duty (Murphy et al. 2005). Accordingly, in reference to the ethics of GTI, consumers should be able to decide if and how much of this information they want to divulge to insurance companies or anyone else.

Another potential moral argument for the “right to privacy” can be derived from Hans Jonas’ (1987) ethical postulate--the “right to not know”. Forcing a person to know her ‘genetic information’ restricts her personal freedom and can be argued to be in violation of her basic right to self-determination. For example, imagine a genetic test that can predict with a very high probability a devastating disease that is incurable. There is no treatment for this malady and there is nothing the person can do. Huntington's disease comes close to this scenario. The disease may present at any age and manifests as a slowly progressive neurodegenerative movement disorder with cognitive and behavioral impairment (Walker 2007). In this case, some people might not want to know at least as long as they don’t have any symptoms (Borna and Avila 1999). Indeed, a majority of patients at risk of inheriting Huntington’s disease feel there is no point in proceeding with testing because there is no recognized treatment (Walker 2007). Asymptomatic patients who decided to get tested for Huntington’s disease were significantly more likely to experience serious catastrophic psychiatric events, including contemplated or actual suicide within two years of receiving the test results. (Almqvist et al. 1999). Considering that in Almqvist’s study patients voluntarily chose to get tested, it is not unreasonable to
assume that *forcing* a person to know her GTI might have even more detrimental consequences for her immediate wellbeing (Bird 1999). Finally, genetic testing can also have a direct impact on the emotional well-being of family members that are not getting tested.

One could also use John Rawls’ *liberty principle* (LP) in an attempt to morally justify that people should have a choice to keep their genetic information private. As long as we assume that keeping one’s genetic information private does not limit the freedom of other people, forcing people to divulge genetic information is restrictive to people’s freedom and not in line with “the most extensive total system of equal basic liberties” (Rawls 1971, 302). A just and fair system—according to the LP--requires that people have as much freedom as possible as long as it does not limit the freedom of others.

- **Malicious mishandling of genetic data:** Abuse of genetic data by corrupt parties such as hackers or unscrupulous testers is another nasty outcome dampened by banning the use of genetic information by insurance companies. For example, as the abuse of medical and other information by online advertisers shows, this danger of data breaches becomes more real. Acquiring (often through dubious methods), storing, and selling medical data by data brokers is a big business (Pettypiece and Robertson 2014; Nill et al. 2015). An argument could be made that an “information ban on GTI” limits the amount of genetic data that is being stored as well as the number of parties that have access to it (researchers, hospitals, insurers, etc.). In turn, there is less opportunity for hackers and rogue parties (such as unscrupulous data re-sellers) to take advantage of sensitive GTI. Clearly, from an ethical “privacy rights” perspective, it is of utmost importance that
genetic data, once collected, be stored and handled in a way to prevent potential abuse. However, it remains arguable whether a total information ban is the best way to prevent the potential exploitation of genetic data.

- **Improper commercial use of genetic data**: Genetic data in the insurance industry are properly used only if the result of the data usage leads to accurate risk classification (people in the same classification have the same risk for the insurer). One of the most obvious arguments for the public policy option of an “information ban on GTI” is to avoid risk classifications based on improper use of genetic information (some people in the same classification are riskier for the insurer than others). If a person is misclassified by an insurance vendor based on their GTI, they risk substantially higher insurance premiums (an economic cost) as well as any psychological costs that manifest from the loss of this information to unauthorized parties. In order to be valid, risk classification has to have a clear and statistically verifiable relationship to ultimate insurance losses. There has been anecdotal evidence that insurance firms used GTI without having established a statistically verifiable relationship to losses (Billings et al. 1992). For example, carriers of certain diseases, who themselves had no higher probability of developing the disease than the general population, have been denied coverage (Hedgecoe 1996). Arguably, in a competitive market where all insurers have a motivation to build an accurate classification system, over time, improper usage should ameliorate (Brockett and Tankersley 1997). This is because those insurers who continuously use inaccurate risk classifications (for example, due to improper use of genetic data) will misprice their insurance premiums and lose out to competitors. However, developing statistically
verified risk classifications can be hampered by not properly interpreting the results of genetic tests. For instance, increasing the premium for policyholders that have a genetically higher probability of cardiovascular disease might lead to a mispriced premium (i.e., the price would be too high) if the genetic test motivates those people to eat healthier, exercise more and seek medical intervention. In such cases, the “positive” test for cardiovascular disease might not lead to a statistically higher chance of manifesting the disease and accordingly, would not lead to higher losses for the insurer.

Further, an accurate interpretation of the clinical significance of genetic tests often requires other clinical information (McPherson 2006).

Possible misclassification of low risk policyholders as ‘high risk’ clearly constitutes “unfair discrimination” in an ethical as well as actuarial sense. Under such a protocol, there would be a significant unfair wealth transfer from those misclassified policyholders to everybody else in the risk pool. From such outcomes, it is easy to see why most ethical frameworks would condemn the improper use of genetic information by insurers. And, from a utilitarian perspective, improper use of genetic information does not advance social welfare. From a Kantian perspective, consistent with a professional ethic to serve and protect their customers, insurers have a moral duty to not cause harm through gross negligence. However, morally justifying an “information ban on GTI” based only on the possibility of misclassification is more problematic. Instead, insurers have a moral duty to reduce the risk of misclassification as much as practically possible (e.g., repeat testing of positive tests).
- **Impact on medical research**: “Although there have been very few documented instances of genetic discrimination in health insurance and employment, the fear of such discrimination has led many at-risk individuals to decline genetic testing in both the clinical and research settings” (Rothstein 2008, 837). People might be less afraid of undergoing genetic testing if the usage of GTI is banned. This argument, one which was used by the U.S. Congress for enacting the Genetic Information Nondiscrimination Act (GINA) (Roberts 2010), might be less prevalent in countries with socialized medicine. However, in countries where private insurance is important, the fear that a ‘bad’ genetic test result will greatly increase one’s health insurance premium, or worse, preclude someone from getting health insurance coverage at all seems quite reasonable. From a purely a utilitarian standpoint, if more people are inclined to get tested, there will be more scientific progress from using the information of gene technology, which is beneficial to everybody including prospective patients. However, as discussed later, an information ban is not necessarily the most efficient way to motivate people to get tested.

- **Early medical diagnosis, treatment and behavioral changes.** Early treatment and behavioral changes triggered by genetic test results are likely to lead to overall better public health. For example, it is well known that the chances of curing breast cancer improve with early detection, which is made possible through a genetic test. While the results of only very few genetic tests allow a deterministic prediction of future disease, “a growing number of tests are being developed to look at multiple genes that may increase or decrease a person’s risk of common diseases, such as cancer or diabetes” (CDC, 2017). Knowing the results might trigger positive behavioral intervention. For example,
if a person finds out she has a higher chance of cardiovascular disease, he might start eating healthier and exercising more. Under the assumption that more people would get tested if insurers were not allowed to use GTI, resulting behavioral changes would be in line with the utilitarian goal of achieving a net positive outcome, i.e., better social health and lower aggregate medical costs being the primary benefits.

- **Genetic Exceptionalism.** Genetic exceptionalism – an expression coined by Thomas Murray (1997) – maintains that genetic information is unique and qualitatively different from other medical information and should be treated as such (Suter 2001; Rothstein 2007). The basic argument here is that our genes define our identity, “make us human, and explain our place in the world” (Suter 2001, 674). Therefore, a person’s genetic information deserves special protection, which greatly extends a person’s right to privacy. The idea of genetic exceptionalism has been one of the cornerstones used by the U.S. Congress to justify the enactment of the Genetic Information Nondiscrimination Act (GINA) (Roberts 2010).

However, in reality, the impact of genes is infinitely more complex than this common assumption about genetic exceptionalism. Most human traits and health outcomes are the interplay between the environment, our behavior, and our genes—nature and nurture. In other words, “a gene in itself can never give rise to the properties of an individual and can only affect an individual given an environment” (Radetzki et al 2003, 12). Epigenetics refers to modification of gene expression triggered by a variety of environmental exposures such diet or air pollution (Rothstein 2013). Since those modified gene expressions, which were originally caused by environmental exposure, can be passed on to offspring for an indeterminate number of generations, the line between
nature and nurture is further obfuscated. Therefore, the popular believe, which is part of the allure of genetic exceptionalism, that our identity, our whole being is defined by our genes has to be refuted.

Further, it is impossible to draw a clear line between genetic and non-genetic medical information (Rothstein 2007). For example, cystic fibrosis is a genetic disorder that is inherited in an autosomal recessive manner. It can be diagnosed with a high probability without genetic testing using a simple chloride test (Radetzki et al 2003). Contrast this with the definition of genetic information used by GINA: Genetic information is “information about an individual’s genetic tests, the genetic tests of family members, and the manifestation of a disease or disorder in family members”. (GINA 2008, §201) Would the chloride test then fit the definition of genetic information?

Indeed, even a working definition of genetic information has become the more elusive, as more of the human genetic code has been deciphered (Rothstein 1999). Thus, if there is no sound basis for separating genetic from non-genetic medical information any rule for protecting some information but not protecting other information is arbitrary. The argument to reject genetic exceptionalism is that while arguably medical information should be protected to some extent in general (see section about right to privacy above), genetic medical information should not be granted special protection. “It is difficult to make a moral argument that it is impermissible to discriminate against people on the basis of genetic information but that it is permissible to do so if the condition is not genetic (Rothstein 2008b, 175).

Finally, it is useful to recall that insurance companies are not primarily interested in causal relations but are interested in statistical correlations that allow assessing their
policyholders’ risk. Even if it were possible to separate genetic from non-genetic information, insurance companies will likely try to sidestep a ban on GTI by finding non-genetic properties that are correlated with genetically high risk populations (Radetzki et al 2003).”

To be sure, certain applications of gene technology such as the cloning of human life or genetically modifying human eggs to “create” designer babies would fall under the auspice of Jonas’ imperative of responsibility (Jonas 1985) because such techniques might open the door to creating a “genetically elite” class of citizens. Widespread use of these technologies could cause major social problems. However, it is more debatable to see how Jonas’ imperative would apply to the argument of genetic exceptionalism in the insurance industry. Allowing or not allowing insurance companies’ access to genetic information alone does not seem to lead to the catastrophic outcomes (i.e., lethal human consequences) that are covered by the imperative of responsibility. Accordingly, it would not seem justified to apply Jonas’ ethical caution here; thus, the action of data collection by health insurers likely would be permitted under his principle.

In sum, from an ethical perspective, the strongest argument brought forward by the proponents of an “information ban on GTI” is the right to privacy, which is supported by several ethical frameworks. While the malicious or negligent mishandling of genetic information poses real risks for society, an information ban is not the only answer to these challenges. Similarly, as discussed later, an information ban is not the only remedy to the ethically valid argument that the use of genetic information by the insurance industry might instill fear, which in turn might slow down medical research or prevent people from taking advantage of early diagnosis/treatment options. Genetic exceptionalism does not lend moral support to an information ban, especially
when trying to justify why normal medical history still *can be* used to classify risk but GTI *cannot be*.

Even using deontological reasoning to justify the “information ban on GTI” can have its pitfalls. One might use John Rawls’ (1971) *veil of ignorance* as a tool of analysis in an effort to morally support an information ban on GTI. A rational person – in a state where the person does not yet know which genes she will end up with – might well believe that not letting insurance companies use genetic information will avoid the worst of possible outcomes (for example, losing health care coverage at a time when it is most needed). Most likely, under the veil of ignorance, a rational decision maker would choose to avoid the direst of outcomes and would be willing to forego some medical information in order to be protected from health insurance loss (Laczniak and Murphy 2008). Thus, in general, Rawlsian analysis would be supportive of a GTI ban. However, the same argument might apply to other non-genetic risk factors we cannot control (Suter 2001). In other words, if we were to summarily accept this Rawlsian analysis, we might also argue for a ban on insurance companies from using *any* other non-genetic medical information. Indeed, some countries including the U.S. post-Affordable Health Care Act (2010) do not allow health insurance companies to use any medical records, including preexisting conditions, for underwriting or pricing decisions. This is in line with the just society as Rawls envisions it that calls on the state for an interventionalist role on behalf of the less well off to get access to the same basic health care the more well off and healthy enjoy (Buchanan et al. 2000). However, Rawls’ does not “deny the possibility that humans differ in natural ability or talent, and no discoveries turned up by the Human Genome Project will undermine this philosophy” (Buchanan 2000, 318).
Does all this suggest that the prevailing norms in the USA are shifting away from a free market approach that relies on efficiently allocating cost among individuals based on accurate risk classification including preexisting conditions and GTI? Perhaps. The current discussion about “repealing and replacing” the Affordable Health Care Act in the U.S. is rife with ethical argumentation about the rights of all citizens to healthcare. And, while the application of Jonas’ imperative of responsibility is uncertain to the facts of this situation, ethical arguments based on human dignity, personal autonomy, and the prevalence of basic rights—i.e., the right to privacy—as well as Rawls’ “difference principle” --provide considerable ethical support for a full information ban on GTI as a viable public policy option to at least be considered.

2. **No Restrictions on GTI**

This approach, the polar opposite of the previous public policy option, does not place any restrictions on how insurance companies can use genetic testing information (GTI). This public policy approach (i.e., minimalist regulation) is one that is a commonly selected approach for many other issues in the USA where suspicion of too much governmental regulation and social engineering runs high. The thinking is that less regulation trumps more restrictions because markets are allowed to function freely, increasing economic efficiency. Of course, each case situation involves different considerations for business and society including that of the insurance industry and its risk classification system. The same arguments supporting an “information ban on GTI” can be used to reject a “no restrictions” policy (see Table 1). And conversely, as in the instance of the “information ban on GTI” where utilitarianism shed some doubt on the pragmatics of that option, with this opposite approach, utilitarian analysis can be used to support a “no restrictions on GTI” approach.
Many Asian including for example Japan, the Philippines, as well as most African countries have not enacted specific legislation regulating the use of genetic information (Joly et al. 2010; Otlowski and Bombard 2012). If insurance companies consider genetic information as a useful and cost effective means to assess the risk of their policy holders, in such markets, they are likely to require genetic tests for underwriting and pricing purposes. That is, in the absence of restrictions or black letter law, insurers will develop risk classifications based on genetic test information. If a potential policyholder were to refuse to provide GTI, the insurer will likely either charge a very high premium or refuse coverage altogether. In other words, insurance companies are inclined to make genetic testing mandatory for prospective policy holders as soon as it becomes feasible to do so. Simply put, if the cost of genetic tests are low enough, it would be economically inefficient to ignore information that can be used to better estimate expected losses (Crocker and Snow 2013; Brockett and Tankersley 1997).

- **Adverse Selection**: “Adverse selection is defined as “an imbalance in an exposure group created when persons who perceive a high probability of loss for themselves seek to buy insurance to a much greater degree than those who perceive a low probability of loss” (IRMI 2016). In other words, when insurance companies are not allowed access to genetic test results but policy holders are free to obtain and privately hold genetic information that may be pertinent to their insurance purchasing, insurers cannot build accurate risk classifications (Durnin et al. 2012). People who know that they suffer from a genetic disorder expect high medical cost in the future. However, if GTI is only known to the policyholder, the insurance company cannot account for the higher risk of those policy holders. Therefore, for policyholders with a known (only known to the policyholder) infliction, the insurance premium is low compared to his expected medical
expenses. It is this information asymmetry that leads to adverse selection. The applicant/policy holder knows of the higher risk, but the insurance company does not”. Therefore, due to this information asymmetry, high risk applicants get coverage at a bargain price (Rothschild and Stiglitz 1976) and healthy applicants are charged too much. It can be reasoned that not allowing insurance companies to use genetic information for developing risk classifications – as in the case of an “information ban” policy option - will engender instances of adverse selection.

Adverse selection can lead to market failure (Dionne and Rothschild 2014; Brockett and Tankersley 1997; Borna and Avila 1999; Cardon and Hendel 2001). In this context, market failure is defined as an equilibrium in which no trade occurs or an equilibrium fails to exist. (Hendren, Econometrica, 2013). In other words, market failure occurs if nobody is willing to buy insurance at the premium offered by the insurer or/and, if no insurer is willing to offer a premium low enough so that people buy the insurance. Adverse selection potentially can lead to this type of market failure.

For example, people who find out through genetic testing that their likely needs for health care are greatly increased have a strong incentive to get comprehensive health insurance coverage. Insurance companies accepting these high risk individuals, without having knowledge of the applicant’s genetic test, will offer them policies with premiums that do not account for the higher risk. As long as insurance companies cannot adjust their pricing reflecting this higher risk, comprehensive coverage is more valuable for genetically inflicted people than people without this infliction. The higher morbidity of this group will increase the overall cost for the insurance company of this risk pool. In turn, the insurance company has to increase premiums for everyone in this risk pool. This
creates a disproportionate disincentive for healthy people to get coverage (i.e., high risk people are less likely to forgo coverage, and lower risk individuals might not want to subsidize higher risk policyholders). Costs for the insurance company will increase. This might trigger another cycle of increasing rates and further defection of low risk clients. In the end, this could even lead to an adverse selection death spiral and to an unraveling of the market, so that no one is insured. The problems of adverse selection can be avoided by allowing insurers to perform proper risk classifications, including the usage of GTI, which may offset the insured’s informational advantage and permit improved economic efficiency (Crocker and Snow 2013).

Interestingly, as noted above, risk discrimination by insurance providers based on pre-existing condition is not allowed in the U.S. (Affordable Health Care for America Act 2010). Arguably, as a consequence of this policy, adverse selection can be already witnessed. Young healthy people disproportionally have been dropping out of the insurance plans, making the risk pool costlier and leading to significant increases in premiums. “As costs rise, more individuals will decide not to buy health plans. That’ll push premiums even higher, unless a new president and lawmakers can find fixes for the new markets created by the 2010 health law” (Tracer and Doherty 2016). Aetna Inc. Chief Executive Officer Mark Bertolini offers a rather dramatic description alluding to the adverse selection death spiral: “What happens is the population gets sicker and sicker and sicker and sicker. The rates keep rising to try and catch it. It’s a fruitless chase, and ultimately you end up with a very bad pool of risk.” (Tracer and Doherty 2016).

While empirical evidence for adverse selection in countries that adopted an information ban on insurers using GTI is still limited (Crocker and Snow 2013), it can be
expected that with the decreasing cost and increasing availability of genetic information tests - including direct-to-consumer testing services - the information asymmetry between consumers and insurers will likely increase. As a consequence, adverse selection will also increase. For example, Zick, et. al (2005) found that individuals who had positive predictive tests for Alzheimer’ disease substantially increased their purchase of long-term care insurance. Oster, et. al (2010) report asymptomatic individuals who have tested positive for Huntington’s disease are five times more likely to own long-term care insurance than otherwise comparable individuals. Similarly, Geller et al. (1996) found anecdotal evidence for asymptomatic carriers of Huntington’s disease to take out extensive health insurance policies. On the other hand, Cardon and Hendel (2001) could not find empirical evidence for adverse selection in purchasing health care coverage using data on single individuals from the National Medical Expenditure Survey.

Clearly, from a purely economic perspective, such outcomes are troublesome. Adverse selection and its potential consequences could be seen as in direct opposition to the utilitarian goal of ‘the greatest happiness for the greatest number of people’. There seems little doubt that from an economic utilitarian standpoint (analysis where the point of reference for management is shareholders and financial), adverse selection will likely reduce insurance company profits. Even under classical utilitarianism (where all stakeholders are at focus) adverse selection might have extreme consequences, with healthy consumers paying more. That is, “the greatest number”—the majority—would be financially disadvantaged under this approach. Indeed, if adverse selection really were to take hold in the market, without structural adjustments via (government) subsidy,
society as a whole could be worse off because health insurance providers might dwindle, and less choice would lead to higher prices and/or reduced coverage.

- **‘Fair discrimination’ via GTI testing** (Borna and Avila 1999; Worthham 1986).

Different people pose different risks for insurance companies. People with less risk factors will ‘on average’ bear less cost to the insurance company than people with more risk factors. According to the argument of fair discrimination or *actuarial fairness*, it is proper to charge people with more risk factors higher premiums than people with less risk factors (Landes 2015; Crocker and Snow 2013). In other words, it would be unfair to the people with low risk factors if everybody were to pay the same (regardless of risk). While the overall concept of fair discrimination is widely accepted, it is the use of actuarial decisions based on GTI that is being debated. For example, using information about smoking habits of policy holders is quite uncontroversial but using genetic information is not. Insurers use personal information to make decisions every day. Yet, for those decisions to constitute "discrimination", in the pejorative sense, people must believe that using that *particular* information is somehow inappropriate (Roberts 2010). Of course, the use of GTI to make insurance decisions that could put health coverage (a basic need) outside the financial reach of many persons—especially poor persons—represents such a special case situation. Rawls *difference principle* would support not adding to the economic burden of those most likely to become sick—persons with GTI known to be positive (a genetic marker associated with future disease likelihood is found)—because (according to Rawls) they would be the “disadvantaged” most deserving of ethical
consideration. People can choose to stop smoking or lose weight. They cannot change their genetic make-up.

Following Rawls’ (1971) second principle - social and economic inequalities are to be arranged so that they are to the greatest benefit of the least advantaged - one might be tempted to argue that shifting the economic burden from the genetically inflicted to the healthy is “fair”. In this instance, the genetically inflicted, who are already at a disadvantage in society by their likely disposition to serious disease, are also being asked to bear the additional burden of greater economic costs. Justice is achieved when “the advantages of the more fortunate promote the wellbeing of the least fortunate” (Rawls 1971, 227). Thus, what may be unfair in an actuarial sense may be quite fair from the standpoint of the individuals in the community/society. This protection from down-side risk (for individuals) is essential to the Rawlsian “justice as fairness” approach.

Other deontological arguments opposing a “no restrictions on GTI” option can be put forward. The concept of “fairness” itself is one of the timeless core virtues introduced by the classic Greek philosophers that can serve as a test for the ethicality for economic outcomes (Laczniak and Murphy 1993). Fairness is also a main principle of distributive justice as well as a central theme of the Judeo-Christian tradition (Ferrell and Ferrell 2008). The core question of distributive justice is about the fairness of how benefits and burdens of exchange decisions are apportioned among various stakeholders (Laczniak and Murphy 2008). Because an information ban on GTI will lead to wealth transfer from the healthy to the genetically inflicted, not allowing insurers to request and use genetic information could be seen as contributing to an avoidable, unfair outcome. In other words, in contrast to an “information ban on GTI”, mandatory testing, inspired by a
“no restrictions on GTI” policy, will more properly shift benefits to the (lower cost) genetically healthy and burdens to the (higher cost) genetically inflicted.

- **Wealth transfer:** Restricting the use of GTI is likely to lead to a wealth transfer from genetically healthy policyholders to policyholders with a genetic infliction. The same mechanism that can cause adverse selection can also lead to a wealth transfer. If the use of GTI is restricted, insurers cannot develop accurate risk classifications in an actuarial sense. This leads to premiums that do not reflect the actual expected losses of individual policyholders. In this case, all policyholders, regardless of their individual genetic risk, would be charged the same premium. That is, people with low risk factors – by paying higher premiums than they would if the use of genetic information were not restricted - are transferring wealth to people with high risk factors. In many cases, policyholders know, or should know, that the wealth transfer is taking place. But if policyholders cannot reasonably be expected to know of this de facto redistribution of wealth, those insurance policies can be seen as deceitful. In other words, it is deceitful if insurers conceal this mechanism that transforms health insurance into a wealth redistribution mechanism due to premiums that do not reflect one’s expected losses (Landes 2015).

From an ethical perspective, *deception* is a clear contradiction to the moral duty of truth telling, which is consistent with Kant’s categorical imperative (1st formulation), as well as the golden rule of almost all major religions. Dishonesty is also wrong according to Aristotelian virtue ethics (Murphy 1999). It is important to point out that it is not the outcome per se – wealth transfer from the healthy to the unhealthy – that is argued here to be morally wrong; it is the potentially *deceptive process* involved to get to this outcome.
To summarize, the assorted deontological arguments that have been discussed to justify an information ban on GTI (see previous section) – the policy option chosen to constrain GTI by so many European countries - might also be used to oppose mandatory testing (i.e., no GTI restrictions whatever). But from a utilitarian perspective, mandatory testing for genetic information means more people get tested and that could likely lead to more beneficial health outcomes (in the aggregate) and better risk classification for insurers.

All told, one of the strongest moral justifications in favor of a “no-restrictions on GTI” public policy is the avoidance of adverse selection, which can be justified on utilitarian grounds. If adverse selection was to become prevalent and, it results in market failure for insurers, it likely will lead to dismal consequences for society as a whole. However, once again, it should be understood that discrimination based on genetic test results is fair in an actuarial but not necessarily in a normative ethical sense. That is, as discussed above, Rawlsian analysis does not lend support to the argument that a wealth transfer from the healthy to the unhealthy is “unfair” in an ethical sense; in fact, from the standpoint of the Rawls’ difference principle, that transfer of wealth is actually a proper ethical outcome because it compensates those least well off (the unhealthy) in a given social system. As for the point that health insurance policies do not disclose that ‘the healthy subsidize the unhealthy’, while non-disclosure can be ethically wrong, this does not automatically translate into a powerful justification for a “no-restrictions on GTI” public policy. Deception can be rectified under any public policy scheme by simply and clearly informing consumers.

In the end, the right to privacy, the strongest argument in favor of policy option #1--an outright information ban on GTI – would clearly be violated by policy option #2--a “no-
restrictions on GTI usage” public policy, despite the advantages of this option for a fairer actuarial allocation of costs and, perhaps, a stimulus to better health behaviors and enhanced medical knowledge.

In the next section, three “compromise” positions, policies lying between the extremes of an “outright ban on GTI” versus “no restrictions on GTI” are discussed. For a summary of all these public policy choices from an ethical standpoint, please see Table 1.

3. **Limited Voluntary Disclosure**

With the “limited voluntary disclosure (LVD)” option to oversee the use of GTI, insurance companies cannot require policy holders to get tested, or reveal any genetic information, or even know the fact that they did get tested. However, policy holders are free to disclose their genetic information to the insurer *if they* decide to get tested. At first glance, this public policy option (#3), offers a lot more privacy, personal freedom, and choice to policy holders than a “no restrictions” on GTI regime, which typically leads to mandatory testing. However, upon closer examination, “limited voluntary disclosure” will invariably lead to the same results as the “no restrictions” option (i.e., mandatory testing). That is, over time, insurers will end up with similar risk classification schemes and policy holders will have almost identical (and limited) insurance choices as in a “no restrictions on GTI” (option #2) regime. Here is why:

As long as the insurer has no access to GTI, there is no risk classification based on genetic information (as in the Full Information Ban option discussed above). Once policyholders are free to disclose their GTI - as in the limited voluntary disclosure option (LVD) insurers can
theoretically build three risk classifications: (1) low risk for policyholders with a negative genetic test result (no indication for higher morbidity). The premium is lowest in this group. (2) medium risk for policy holders whose GTI is unknown. The premium is medium for this risk pool. (3) high risk for policyholders with a positive genetic test result (indicates a potentially higher morbidity). The premium is highest for this risk pool.

Accordingly, people who get a negative genetic test result (no genetic inflictions found) have a financial incentive to reveal the GTI to the insurance company; they will be able to switch to the lower risk pool, which is associated with a lower premium. People with a positive genetic test result (genetic inflictions found) have a financial incentive to keep that information private. Nobody wants to switch to a higher risk pool and pay a higher premium. Therefore, since nobody is going to reveal a positive test result, initially, the insurer will end up with two risk pools:

Pool 1, people who got a “negative” test (low premium costs) and Pool 2, people who got a “positive” test –a genetic marker associated with future disease likelihood–plus people who did not get tested (higher premium costs). From the perspective of the policy holder, this expected insurance cost differential provides a strong incentive to get tested since there is minimal downside. If the result is negative, you share the GTI and your premium is lower; but if the GTI indicates a positive result for major disease disposition, you don’t reveal the test and your premium will stay the same. As more people decide to get tested, healthier people will disclose, which means they move from the second pool (high premium) to the first pool (low premium); of course, those with a genetic affliction will not tell and stay in the second pool. In turn, the risk in the second pool (i.e., people who got a positive test along with people who did not get tested) will go up since the relative number of known genetically marked people will increase versus the number of untested people in this pool. This in turn will induce the insurer to
further *raise* the premium for the second pool – thereby increasing the price differential -
triggering yet another round of testing. *Perhaps*, once a critical mass of people has been tested,
insurers might start developing more risk pools for people with minor or moderate afflictions
(medium premiums), thus providing an incentive for some policy holders to leave the high risk
pool. Over time, almost everybody will get tested and almost everybody (with the exception of
the most severely afflicted policyholders) will voluntarily share their GTI.

Therefore, in the long run, as tests become ever more practically available, this policy
option #3 (LVD) will lead to a very similar risk classification scheme as option #2 and be prone
to the same criticisms from an ethical theory perspective. In other words, the same ethical
arguments that apply to a “no restrictions on GTI” option also apply to the “LVD policy for
GTI” (option #3). (See **Table1**).

It is interesting to note that the U.S. congress introduced a new bill - H.R. 1313 – that
would allow employers to offer substantial health insurance premium rebates to workers who
take part in a voluntary company wellness programs, which require workers to undergo genetic
testing. Workers who refuse to reveal their GTI cannot take part in the wellness program and
must pay a substantially higher premium. In the end, similar to the dynamics discussed in a
Limited Voluntary Disclosure scheme, employees, who do not suspect to suffer from a genetic
infliction or who already know because they got tested elsewhere, would have a strong financial
incentive to take part in the wellness program. If this bill were to become law, the protections
under GINA would be seriously undermined (Sun 2017).

At first glance, policy option #3—limited voluntary disclosure - appears to offer much
more privacy and autonomy to policyholders than a “no restrictions on GTI” (mandatory testing)
regime. However, as discussed above, the LVD approach amounts to not much more than “bait
and switch”. Dressing up the “no restrictions” regime (option #2) as “LVD” also might be considered an ethically questionable way of getting public approval for this policy choice, since most consumers do not realize (at first) that it results in the same long term outcome. Regardless, there likely is a deceptive process involved, violating virtue ethics, Kant’s categorical imperative, and other ethical frameworks. Once in place, and after people find out about the true nature of this policy (#3), they might feel they have been duped. Therefore, as a public policy choice, LVD should be recognized as deceptive according to most moral frameworks.

4. Code of Conduct

Policy option #4, labeled ‘code of conduct’ for GTI allows insurance companies to require policy holders to disclose if they have taken a genetic test but not demand the results of the test. That is, individuals must reveal the fact that they took a test but insurance companies do not have access to the specific results. Initially insurers will end up with two risk pools: Pool 1 (people who did not get tested) and Pool 2 (people who did get tested). There is no information asymmetry in Pool 1. The insurer knows as much as the policy holder and will charge an average premium accounting for healthy and inflicted people in the pool. But in Pool 2 people know if they suffer from a genetic infliction or not. The insurer does not know who is afflicted and who isn’t. However, the insurer knows that this pool consists of people who all know if they have an unsatisfactory genetic test or not. Therefore, for Pool 2, the insurer can start offering two (new) policies: A low premium, low coverage policy designed for those who do not have a genetic infliction and a high premium, extensive coverage policy designed for those with a positive genetic test. The logic is that if you know you suffer from a genetic infliction you are likely to desire insurance with extensive coverage. If you know you are healthy you might prefer a more
basic coverage. The extensive coverage policy in Pool 2 will be more expensive than the same policy in Pool 1 while the low coverage policy will be cheaper in Pool 2 than in Pool 1. The reason of course is that many policyholders in Pool 2, who ask for the extensive coverage policy, are ‘on average’ riskier (i.e., they know that they have a genetic affliction) than policyholders in Pool 1.

While different from an “information ban on GTI” policy (option #1), a “code of conduct” program (option #4) allows insurers to develop some risk classifications based on genetic information; those risk classes are likely to be more imprecise and more prone to error than in a “no restrictions on GTI” option (#2) or with the “LVD” regime (option #3). For example, it is not clear if and how the average risk in Pool 1 is affected by offering policy choices in Pool 2. However, over time, as those who learn that they suffer from a genetic affliction opt for a policy with extensive coverage, insurers will be indirectly alerted to the distribution of “genetically afflicted” versus those who have received a “genetically clean” bill of health.

From an ethical perspective, this policy option (#4) does not seem superior to an “information ban on GTI” (policy #1) or even “no restrictions on GTI use” (policy option #2). Again see Table 1. Even though offering more client privacy than mandatory testing, with option #4, people are still being placed in genetic risk categories, potentially without knowing about it. Furthermore, the probable process of risk classification used by this policy choice opens the door for improper use of genetic data. Why is this true? Because on the basis of the coverage chosen by the customer, the insurer assumes they know the client’s general GTI outcome. Although it is difficult to assess the full impact a “code of conduct” policy (option #4) will have on the number of people who will seek to get tested, by having to disclose that a policyholder/applicant has
been tested without really knowing how the insurance uses this information creates considerable unease. Specifically, the client who has GTI which is good-health affirming, informs the insurance company that they have been tested but they do not know (nor are they told) if they have been appropriately classified. While, in a crude way, the information asymmetry between policy holders and insurers is somewhat reduced (i.e., the fact of testing is known to both parties), some “adverse selection”—an ethically and economically problematic outcome-- cannot be avoided under this policy regime. Similarly, the problem of surreptitious wealth transfer is ameliorated but not resolved. Finally, this policy option is potentially deceptive since many policy holders are not likely to understand what they signed up for.

5. Duty to Disclose

In a ‘duty to disclose’ (DtD) GTI (option #5), policy holders have a choice whether they want to get a genetic test or not. Insurance companies cannot require individuals to get tested. However, insurance companies can require individuals who did get tested to disclose their results. That is, policy holders have a choice whether to find out about their genetic map but once they decide to get tested, insurance companies are allowed to have access to their genetic information. Canada, Australia and New Zealand have regulations similar to a ‘duty to disclose’ regime. In this scenario, insurers will initially end up with two risk pools: As in a code of conduct regime (option #4), Pool 1 contains people who did not get tested and Pool 2 people who did get tested. However, unlike in a code of conduct policy, there is no information asymmetry in either pool. Insurers will offer policies accounting for the average risk in Pool 1 but will also be able to develop precise risk classifications along with risk adjusted premiums for Pool 2 (those who choose to get tested and then must disclose).
In the end, from an ethical and societal perspective, this policy choice (#5) might offer more advantages and avoid more disadvantages than the other policy options (see Table 1). To be sure, a DtD scheme does not protect people’s privacy as much as a full “information ban on GTI” (option #1). However, unlike a no restriction on GTI (option #2) or a LVD policy (#3), it does not directly violate people’s right to privacy to the same degree. Policyholders still have a choice whether they want to get tested. Their “right to not know” remains intact, consistent with arguments of ethicist Jonas (1987). By largely avoiding the most egregious personal privacy concerns, “duty to disclose” offers a distinct advantage over “no-restrictions on GTI” or the LVD option. While still a valid concern under option #5, the malicious and negligent handling of genetic information is a more universal problem--applying to medical information in general--that is not specific to this policy choice. In contrast to the “code of conduct” (option #4) and LVD regimes (option #3), this policy offers at least some transparency. That is, the policyholder knows what data is being collected and (in theory) how the data is being used.

This “duty to disclose” GTI (option #5) is also likely to escape potential societal and ethical problems stemming from adverse selection. In this respect, this policy provides for a significant advantage over an information ban—option #1. Since consumers have to disclose their test results when get tested, information asymmetry is largely avoided. This in turn would drastically reduce the wealth transfer from low risk to high risk policyholders created by “adverse selection”. Furthermore, a “duty to disclose” policy is relatively easy to understand and, accordingly, not likely to be perceived as deceptive by policyholders.

It is helpful to realize that a DtD genetic information (policy option #5) evades some of the strongest ethical arguments against an information ban (option #1)—i.e., adverse selection,
and, at the same time, avoids the main moral pitfall of both a no-restriction on GTI (option #2) and the LVD approach: violation of the right to privacy.

Summary and Conclusions

The exercise of practical ethical analysis to morally evaluate complex social choices has a long tradition in moral philosophy (Herman 1993). In this instance, five public policy options to constrain and govern the use of genetic testing information (GTI) by insurance companies are assessed. The importance of this exercise has been hastened by the rapid progress in genetic mapping that will lead to more economically efficient genetic testing that ascertains the health dispositions of individuals. The easier availability of genetic tests and the concomitant pressure to reduce healthcare cost will likely cause both industry and politicians to revisit current policies of overseeing the use of GTI, even in countries were current policies are enshrined in law.

This paper analyzes the five logical public policy options for GTI oversight from an ethical and societal perspective. The “value added” measure for such exercises in moral reasoning is not metaphysical certainty about the issue at focus but rather whether the applied ethical reasoning presented helps decision-makers come to more informed judgments. Using both teleological/consequentialist approaches (primarily utilitarianism) and deontological approaches (especially Rawlsian justice and Jonasian responsibility), the advantages and disadvantages of GTI use by insurers are analyzed from an ethical and social viewpoint. To our knowledge, the ethical perspectives of the philosopher Hans Jonas (1979) have not previously been used in a business context, and this novel application might motivate further usage of Jonas’ philosophy in business ethics.
Our ethical reasoning suggests that an “information ban on GTI” by insurers (option #1) has the strongest ethical grounding. However, as pressures to disclose individual GTI information become greater, due to the usefulness of personal GTI leading to custom patient treatments as well as in general public health research, the “duty to disclose” (option #5), currently favored in countries such as Canada and Australia, will become more admired. The above analysis suggests that “duty to disclose” (DtD), while ethically less pure than the outright “information ban on GTI” option, also has considerable ethical merit from a societal standpoint as it allows genetic information to inform individually tailored medical interventions or behavior changes, thereby improving aggregate public health while reducing healthcare costs.
Compliance with Ethical Standards

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Table 1.

Rating of the five policy choices from a societal and ethical perspective.

<table>
<thead>
<tr>
<th>Moral / Societal Issue</th>
<th>Public Policy Choice</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Information Ban</td>
</tr>
<tr>
<td>Right to Privacy</td>
<td>+</td>
</tr>
<tr>
<td>Malicious mishandling of genetic data</td>
<td>+</td>
</tr>
<tr>
<td>Improper commercial use of genetic data</td>
<td>+</td>
</tr>
<tr>
<td>Impact on medical research</td>
<td>0</td>
</tr>
<tr>
<td>Early medical diagnosis, treatment and behavioral changes.</td>
<td>0</td>
</tr>
<tr>
<td>Genetic Exceptionalism</td>
<td>+</td>
</tr>
<tr>
<td>Adverse Selection</td>
<td>-</td>
</tr>
<tr>
<td>Fair discrimination</td>
<td>-</td>
</tr>
<tr>
<td>Surreptitious wealth transfer</td>
<td>-</td>
</tr>
<tr>
<td>Understandability of policy and its consequences</td>
<td>+</td>
</tr>
</tbody>
</table>

+ Issue does not raise major ethical / societal concerns
0 Issue raises some ethical / societal concerns
- Issue raises major ethical / societal concerns