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Governing the Risks Emerging From the Non-Medical Uses of Genetic Testing

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Abstract

This paper investigates the risks and benefits associated with the use of genetic testing by agents outside the boundaries of the medical sphere and for reasons other than providing health care. Section one considers the actual and potential use of genetic testing by employers, insurance companies, educators, immigration officials and law enforcement agencies. Section two identifies the common risks that arise from all these uses of genetic testing including the risk to genetic privacy and confidentiality, the risk of genetic discrimination, the risk of creating a social polarisation between the genetically advantaged and genetically disadvantaged and the risk of creating a genetic surveillance society. This discussion on the common risks associated with genetic testing is imbricated with a number of policy recommendations that may assist in maximising the benefits and minimising the risks associated with the non-medical applications of genetic testing. In developing these recommendations, the aim is not to prohibit genetic testing and forego the many benefits testing offers individuals and society, but rather, to alleviate some of the fears and misunderstandings of gene technology and to create an environment in which genetic testing can be used to promote the interests of both individuals and society.

Keywords: non-medical genetic testing; genetic privacy; genetic discrimination; genetic surveillance; society; technology; risk

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Introduction

One of the early expectations of human genome research was to generate knowledge that would assist in developing more accurate and efficient diagnostic tests. The expectation was that genetic diagnostic tests would identify asymptomatic individuals carrying disease mutations, which could be followed by prophylactic treatment regimes or lifestyle changes. Alternatively, testing would confirm the diagnosis of symptomatic individuals, which would alleviate the anxiety of uncertainty, reduce diagnostic uncertainty and facilitate a more accurate and individualised approach to treatment. Thus, genetic testing in the medical context offers many benefits for improving health and enhancing the quality of life for individuals affected by a gene mutation. However, as the number, awareness and accuracy of genetic tests increases, and as the costs decrease, the potential for agents and institutions outside the medical sphere to use genetic testing to obtain private genetic information about an individual also increases. Social agents and institutions including employers, insurance companies, educational institutions, immigration officials and law enforcement agencies may present a legitimate reason for requesting a genetic test to obtain information about a person's unique genetic profile. By requesting genetic information, these agents generate a conflict between the right of individuals to maintain genetic privacy and the right of social authorities to obtain or access genetic information.

The aim of this paper is to explore the options for governing the risks emerging from the non-medical uses of genetic testing. To achieve this, the paper is divided into two sections. Section one offers a critical review of the actual and potential use of genetic testing by employers, insurance companies, educators, immigration officials and law enforcement agencies. Section two identifies the common risks and central concerns that arise in all these applications of genetic testing. This discussion on the common risks associated with genetic testing is imbricated with a number of recommendations that may assist policy-makers design policies for governing the use of genetic tests.

Genetic Testing in Employment

Genetic testing may be used by employers to achieve two different aims. First, testing prospective or incumbent employees for disease genes may be used to reduce the financial costs of absenteeism and lost productivity and the administrative cost of recruiting and training temporary or permanent replacement staff. Second, screening employees for genes that confer a hypersusceptibility or hypersensitivity to workplace allergens, toxins, mutagens or teratogens may be used to promote occupational health and safety and to reduce the volume and cost of compensation claims for workplace acquired injury or illness (Faden & Kass 1993; Pagnatarro 2001; Rothstein 1990).

The use of genetic testing in employment is highly controversial because it presents a risk to genetic privacy and genetic innocence. Genetic testing reveals highly sensitive and private information about a person's risk of developing a genetic disease and many individuals prefer to live without the knowledge that they carry a disease mutation. Empirical studies have shown that when faced with the choice to be, or not to be, tested for a gene mutation, many individuals elect not to be tested (Beckwith & Alper 1998). For these individuals, maintaining genetic innocence is preferable to gaining genetic knowledge. This right to genetic innocence is placed at risk by the use of genetic testing by employers, and for prospective employees in particular, it makes little difference whether this testing is compulsory or voluntary because applicants will most likely perceive refusal to consent to the test as jeopardizing their chance of being offered the job (Draper 1999; Otlowski 2002).

In addition to the risk to genetic privacy, genetic testing in employment also engenders a risk of genetic discrimination. This occurs when a prospective employee is denied a job opportunity or current employee is denied promotion based on the result of a genetic test. A person testing positive for the Huntington mutation for example, may be denied a job opportunity because the employer wants to avoid the cost of employing and training a person who is at risk of developing a future neurodegenerative disease.

Critics argue that although employers have a right to test prospective employees for their current ability to perform the job they do not have a right to test for a genetic condition that may develop at some time in the future. In technical terms, employers may test phenotype but not genotype. Furthermore, to discriminate against an individual on the basis of a highly speculative genetic test is described as unfair discrimination because an individual without the mutation may be equally likely to be physically or mentally harmed in an accident or as a result of exposure to an infectious agent and hence, equally likely to be unable to perform the job in the future.

Despite this risk to privacy and the risk of discrimination, genetic testing can be advantageous for employees when used to promote occupational health and safety. For example, before accepting a job as a fire-fighter, it may be advantageous for an individual to know they have the alpha-1-antitrypsin mutation and hence to know they are hypersusceptible to emphysema in a smoky environment. Thus, provided privacy is respected and confidentiality is assured, the test is conducted with informed consent and counselling is offered, the test is performed by an accredited testing laboratory to ensure analytic validity, the individual retains the right to refuse testing and the individual is not coerced by the fear of demotion or dismissal, the idea of employers having access to specific genetic tests to promote occupational health and safety may be justified.

The benefits of using genetic testing to promote occupational health and safety are lost when the test becomes coercive or compulsory. There is a general consensus that compulsory testing should be prohibited except in rare circumstances where the safety of colleagues or the public is at risk. For example, pilots may be required to undergo compulsory testing for a gene that predisposes to epilepsy because in this case, public safety trumps personal privacy. In these situations, employees surrender certain rights when they voluntarily agree to enter into the employment contract.

The benefits are also lost when testing is used as a cost saving measure for employers rather than a tool for empowering employees. Legal safeguards are necessary to ensure that employers do not use genetic susceptibility tests as a substitute for providing a safe work environment for all employees. Policies must be designed to reflect the principle that the employer's right to use genetic testing is conditional upon their responsibility to provide a safe environment.

Most discussions on the use of genetic testing in employment focus on the potential risks to employees, and while these demand careful consideration, it should be acknowledged that employers also face a number of risks. Employers face a conflict between using genetic tests to inform employees of potential risks and using genetic tests to protect employees from potential hazards. If voluntary tests are offered to inform employees of potential risks, then employers are exposed to claims of discrimination and privacy violations. However, if testing is not offered to protect employees against workplace risks, then employers are exposed to claims of negligence. Thus, if testing is to be offered on a voluntary basis only, then employers must be protected from the risk of future workers' compensation claims or claims of negligence from employees who elect not to be tested and who later develop a disease

that could have been prevented. Records must be kept to demonstrate that the test was offered and the benefits explained, but the employee declined the offer.

Genetic Testing in Health and Life Insurance

The use of genetic testing in health and life insurance offers risks and benefits for insurance companies, individuals and society. These differ from the risks and benefits identified in the employment context because the relationship between insurer and insured is very different from the relationship between employer and employee. Customers pay premiums in exchange for an insurance policy whereas employees are paid a salary in exchange for their labour service. In sum, customers pay, employees are paid.

For private insurance assessors, the major benefit of using genetic testing is the ability to protect the viability of the insurance fund. This may be achieved by excluding high risk individuals from the fund, thus avoiding excessive claims on the fund, or by adjusting individual premiums to reflect individual risk, thus maintaining the principle of actuarial fairness that states that low risk people pay less and high risk people pay more (Daniels 2004). The major risk for insurance companies is adverse selection, defined as people using genetic tests to determine if they are at risk of a genetic disease and deciding to enter into, or exit from, the insurance contract based on the result (Zick et al. 2000).

For individuals, the potential benefit of genetic testing in insurance is that people previously denied insurance, offered conditional insurance or insurance with specific exceptions because of a family history of a genetic disease, will have the opportunity to undergo a genetic test for the mutation and if negative, they will qualify for standard insurance cover. For those who test positive, this benefit does not apply. However, those individuals who test positive may still benefit if the disease onset can be delayed or the symptoms treated. To offer an example, an individual with undiagnosed and untreated hypercholesterolemia is a higher risk to an insurance company than a person who has the genetic test and adjusts their lifestyle to manage their blood cholesterol. Thus, having a test and adopting prophylactic measures lowers a person's risk and lowers the chance that the individual will claim on the fund. For insurance companies this creates a dilemma because they are told to credit all favourable genetic information so that more people can obtain insurance cover and at the same time, they are told that unfavourable genetic information must be ignored.

As with employment testing, one of the major risks associated with pre-insurance genetic testing is that individuals may be coerced into having a genetic test and learning about their genetic risk by insurance companies, which negates their right to genetic privacy and right to retain genetic innocence. Coercion may be direct, by making the test a condition of the policy or it may be insidious, by offering the incentive of reduced premiums to people who agree to the test and who test negative.

A second risk arising from the use of genetic tests in insurance is the risk of genetic discrimination, defined as excluding people from the fund, raising premiums or offering conditional insurance based on the results of a genetic test. Based on the principle of moral fairness rather than actuarial fairness, genetic discrimination is generally perceived as unfair discrimination because unlike people who engage in high risk sporting activities or people who choose to live an unhealthy lifestyle, people do not choose their inheritance and cannot change their genes. In addition, international authorities such as the World Health Organization argue that access to a minimum level of health care is a basic human right (WHO 2002). Basic health services should be available to all people, not just those with an error free genome and since access to health services depends on access to health insurance, health insurance must be considered a basic human right. To deny health

insurance to people with a gene mutation would be to deny medical treatment to those who may need it the most.

Genetic Testing in Education

The actual and potential use of genetic testing in a school environment raises a different set of problems to those encountered in employment and insurance because the testing is administered on minors and because unlike employment and insurance, school attendance is compulsory.

Genetic tests may be used in education for four reasons. First, they may be used to diagnose learning disorders such as dyslexia or fragile X syndrome and thus to provide a child susceptible to these conditions with early remedial teaching. Second, the tests could diagnose behavioural or disciplinary problems such as attention deficit hyperactivity disorder (ADHD) and thus to commence a behavioural management program or course of drug therapy to assist an affected child's learning potential. Third, the tests may assist public health researchers and genetic epidemiologists determine the frequency and geographical distribution of specific gene mutations, thus providing essential empirical data for policy makers, whose role is to plan for the future health needs of society. Finally, genetic screening for recessive or X-linked mutations may be offered to senior students as part of a genetics awareness campaign designed to educate young students about the risks and benefits of gene technology and to inform the next generation of parents on ways to avoid repro-genetic risk (Rothstein 1997a).

Despite these potential benefits to students and to public health, genetic testing in a school environment carries an especially high risk of labelling, stigma and altered expectations. Children are especially vulnerable to the negative social and psychological effects of labels and stigma, either imposed on themselves or by others. Like gender and ethnicity, a person's genetic profile can be a powerful influence in the formation of self-identity, and knowledge of adverse genetic information can lead to self-stigma and a problematic self-identity (Suter 1993; Weinberg 1992). Children who differ from the 'norm' often experience rejection by their school peers, even when this difference seems trivial. Exposing children to genetic tests and creating a new classification of individuals labelled 'at-genetic-risk' opens up new opportunities for creating boundaries of inclusion and exclusion. The experience of children diagnosed with HIV serves as a warning that despite attempts to dispel fears, irrational discrimination against difference continues (Nelkin & Hilgartner 1986).

Genetic testing by educators also carries a risk of avoiding responsibility for poor academic performance, or shifting responsibility from schools to physicians. As Nelkin observed, explaining poor academic performance as a genetic condition rather than an effect of the environment embodies a risk that people will adopt the view that "responsibility should fall to the medical system, not to the schools" (Nelkin 1999). Appeals to genetic determinism release students, parents, schools, teachers and policy-makers from responsibility for poor academic performance because they can explain the failure as a medical condition and blame the failure on inferior genes. This medicalisation or geneticisation of learning disabilities is appealing because of its perceived objectivity, scientific legitimacy and simplicity.

Genetic testing in education is more problematic than genetic testing in employment and insurance because it involves the testing of minors. Most advisory bodies have recommended that the genetic testing of children should not be performed unless there is an immediate medical benefit. For example, the Institute of Medicine Committee on Assessing Genetic Risks recommends that: "childhood screening is not appropriate for carrier status,

untreatable childhood diseases, and late-onset diseases that cannot be prevented or forestalled by early treatment" (Andrews 1994, p. 276). Similarly, the American Academy of Paediatrics "does not support the broad use of carrier testing or screening in children or adolescents" (AAP 2001). Finally, the Clinical Genetics Society in the United Kingdom has advised that "formal genetic testing should generally wait until the 'children' request such tests for themselves, as autonomous adults" (Clarke et al. 1994).

These recommendations are justified because of the potential for psychological, social and financial harm to the child and because genetic testing violates the child's future right to make the autonomous decision to be, or not to be, tested. In more general terms, genetic testing takes away a child's right to an open future (Feinberg 1980). Once a child has been tested, s/he is exposed to the future possibility of genetic stigmatisation and discrimination in employment, insurance, immigration and marriage.

Genetic Testing by Immigration Officials

Although the use of medical testing by immigration officials has a long history, it has been under-explored in the literature on genetic testing. Genetic testing may be used by immigration officials for two reasons: first, to assess the health status of applicants, or second, to legitimate family relations, detect false identities and reduce fraudulent claims (ALRC 2001; Nelkin and Andrews 1999).

Pre-immigration testing for infectious diseases has long been justified as a quarantine procedure because of the risk of causing harm to others and the risk to public health. Following this precedent of infectious diseases control, pre-immigration testing for genetic diseases may also be justified because of the potential harm to others and additional burden on the public health system. An individual with a genetic mutation can harm others because a genetic disease is a vertically transmissible disease directly affecting the health of offspring, a genetic disease can harm the life a partner who must share the responsibility of caring for a child born with a genetic disorder, and a genetic disease can burden taxpayers who ultimately support individuals dependent on health and welfare services because of a chronic genetic disease or disability.

Despite this public health advantage, pre-immigration genetic testing engenders a social risk of exclusion and discrimination and political risk of being perceived as a return of state administered eugenic policies. Embodied in statutes such as the US Immigration Restriction Act 1927, and policies such as the Australian White Australia Policy, the old racial eugenic policies enforced restricted immigration. The explicit goal of these policies was to construct genetic boundaries, to restrict the entry of genetic foreigners and to safeguard the nation's gene pool (Hasian 1996; Kevles 1986; Lynn 2001; Paul 1998).

Genetic testing may also be used in immigration to legitimate familial relations. Kinship testing offers the advantage of providing a rapid and unambiguous identification of consanguinity which may assist in re-uniting families separated by geospatial and geopolitical boundaries. Accompanying this benefit however, there is a risk that kinship testing will reveal unknown cases of non-paternity. For example, an individual applying to immigrate to be re-united with his or her family of orientation may discover that the person they believed to be their biological father was not their biological father. Alternatively, a father applying to be re-united with his family of procreation may discover that the person he believed to be his biological child was not the carrier of his paternal genes.

Furthermore, there is a risk that this policy of kinship testing gives priority to the biological family or molecular family and neglects adopted relationships. This implies that relationships

based on biological bonds receive greater social acceptance and legitimacy than relationships based on adoption. In turn, this may reinforce the inferior status of adoption in a society that places greater emphasis on genetic relations and may reinforce the inferior status and genetic alienation many adoptees experience.

A further risk is that unlike health testing, which is financed by the state, the cost of kinship testing must be covered by the applicant. Hence, inequalities will be introduced and the poor will be disadvantaged because priority will be given to applicants who can self-finance the test.

Genetic Testing by Law Enforcement Agencies

The prevention and detection of illegal immigrants is just one of the many ways genetic testing may be used to enforce the law and identify offenders of the law. DNA profiling is now widely used to identify or eliminate a suspect in a criminal investigation by matching samples taken from a suspect with samples taken from a crime scene or victim. DNA testing may be used to appeal a conviction and exonerate a convicted person, especially where the person was convicted before DNA technology was available. DNA technology may be used in a mass screen of hundreds of individuals in a workplace, neighbourhood or locality where a serious crime has taken place (Nelkin and Andrews 1999). DNA identification may be used to identify deceased persons or human remains where, due to the cause of death or delay in locating the body, the deceased is no longer recognisable. Finally, DNA identification may be used to identify missing persons, homicide victims or victims of a terrorist attack or mass disaster (ALRC 2001).

Forensic testing is different from genetic testing in employment, insurance, education and immigration for three reasons. First, the use of genetic testing by employers, insurers, educators and immigration officials is still largely speculative, whereas the use of DNA profiling by forensic investigators is now widespread, well organised and routine. Second, there is a significant level of resistance to the use of genetic testing by employers, insurers, educators and immigration officials, whereas there is a high level of support for the use of genetic testing by forensic scientists to identify or eliminate a suspect in a criminal investigation. Third, because DNA profiles are obtained from non-coding regions of DNA, the tests do not reveal the presence or absence of a disease mutation. Therefore, the problem of violating an individual's right not to know if they carry a disease gene, or labelling an individual as 'at-genetic-risk' and exposing the individual to the social stigma associated with the 'at-genetic-risk' label does not arise. However, the stigma associated with being a suspect in a criminal investigation remains.

Despite the benefits of using gene technology to assist in identifying suspects, solving crimes and convicting criminals, forensic DNA profiling is not risk free. There is a small technical risk that due to sample contamination, faulty labelling or technician error, the forensic laboratory may return a false-positive or false-negative test result and hence a risk that the innocent may be found guilty or the guilty innocent. There is also a risk that judges and jurors have little or no expertise in the critical evaluation of scientific evidence and little understanding of the probabilistic information revealed by genetic tests (Rothstein 1999). Finally, there is a risk that the validity of DNA evidence conflicts with the accuracy of eyewitness and other testimony, thereby creating a conflict between competing truth claims and hence, reasonable doubt in the minds of judge and jury (Lynch and McNally 2003).

In future years, DNA testing may also be used to detect individuals predisposed to violent, aggressive or criminal behaviour. A number of researchers in behavioural genetics claim to have identified genes that confer on the individual an elevated propensity to engage in

criminal behaviour. The first major study suggesting a genetic link to crime came from a research group in Edinburgh (Burke 1969). The researchers hypothesized that males with an extra Y chromosome, or XYY males, were more likely to be found in prisons than are normal XY males because the extra Y chromosome would increase the level of male hormones and hence, increase the expression of aggressive male behaviour. One hundred and ninety seven males described as dangerously violent were karyotyped and seven were found to have the XYY karyotype.

The medicalisation or geneticisation of criminal behaviour continued in 1993 when a Dutch geneticist reported on a large family with eight males predisposed to extremely violent behaviour. All the violent males had a defect in the gene coding for monoamine oxidase A, an enzyme that degrades the neurotransmitters serotonin and norepinephrine. None of the non-violent family members had this defect (Brunner 1993).

Although testing for a 'propensity to engage in criminal behaviour' trait is still in the domain of science fiction rather than science fact, one of the anticipated risks is that prospective parents may request the test as a prenatal genetic test and may decide to abort if the gene is present. The foetus will be presumed guilty whilst still innocent, tried without any defence, convicted without evidence and executed for a crime that has never taken place. Similarly, employers, educators and immigration officials may use the 'propensity to engage in criminal behaviour' gene to exclude individuals so identified from employment, education or immigration. Innocent individuals will be labelled, excluded, sequestered or sanctioned for inheriting a faulty gene.

If future scientists succeed in identifying a reliable 'propensity to engage in criminal behaviour' mutation and if they succeed in developing an accurate diagnostic test, then the possibility arises that scientists will use the same knowledge about the expression, regulation and function of the 'crime gene' to develop psychotropic drugs or gene therapy to prevent the expression of aggressive, impulsive, violent or criminal behaviour. A series of hypothetical questions then arise including: should the emphasis be on prevention or cure? Second, if the emphasis is on prevention, should pre-natal testing for the crime gene and termination where the crime gene is detected be enforced by the state as part of a crime risk management policy? Would this signal a return to the eugenic policies of the past? Third, if the emphasis is on a cure, and the idea of compulsory testing is rejected, then should society make anti-crime therapy compulsory for those individuals diagnosed with the 'propensity to engage in criminal behaviour' gene? Finally, given the aversion to compulsory therapy, should society allow innocent individuals diagnosed with the 'propensity to engage in criminal behaviour' gene the choice between incarceration without therapy or therapy without incarceration?

Finally, there is a risk of following what is commonly referred to as the slippery slope or technological imperative. That is, there is a risk that DNA profiling will initially be restricted to prisoners convicted for serious crimes, then broadened to prisoners convicted for less serious crimes, then extended to parolees, then to suspected criminals and ultimately to all citizens. Indeed, there is a risk that a DNA profile of each individual will be collected at birth, stamped on a person's birth certificate and entered into a national database, thus creating a national genetic identification database.

Common Risks Arising From The Use Of Genetic Testing In Employment, Insurance, Education, Immigration And Law Enforcement

From this exploration of the use of genetic testing by employers, insurance companies, educators, immigration officials and law enforcement agencies, a number of common risks emerge. These include: the risk to genetic privacy and the risk of genetic discrimination; the risk of coercive or compulsory testing; the loss of trust in social authorities to keep genetic information confidential; the risk of misunderstanding, misinterpreting or overestimating the information obtained from genetic tests; the risk of creating a social inequality between the genetically advantaged and genetically disadvantaged; and the risk gene technology will be misused as an insidious tool of social surveillance rather than used as an instrument to further the enlightenment goals of liberation and empowerment for individuals.

Genetic Privacy

Genetic technology is not the first technology to challenge privacy rights. Printing, photography, audio and video recording, X-ray, ultrasound and infrared imaging and information technology also threaten the rights of individuals to physical, informational, decisional and proprietary privacy (Allen 1997). Genetic technology does however give rise to a unique form of genetic privacy, defined as the inappropriate or involuntary disclosure of the information coded in an individual's genome. As the availability and affordability of genetic tests increases, as the number of social institutions using genetic surveillance increases, as the volume of genetic information stored in electronic databases increases and as more individuals learn about their unique genetic profile through genetic tests, the risk to genetic privacy intensifies. With this intensification comes the need for greater protection of genetic privacy rights. Without privacy protection, an individual's right to know, their right not to know, and their right to make autonomous decisions about the disclosure of highly sensitive and consequential information is at risk.

Whilst there is a general consensus on the need to protect genetic privacy, designing effective and equitable policies for the protection of genetic privacy is exceptionally difficult to achieve because there are many situations where one agent's right to genetic privacy conflicts with another agent's equal and opposite right to genetic information (Rothstein 1998). Indeed there are many situations in which the right to genetic privacy is not absolute but rather, the right to genetic information trumps the right to genetic privacy. In the context of employment for example, individual genetic privacy may be violated to protect the health and safety of co-workers or the wider public. In the context of insurance, fund managers have a responsibility to other policy-holders and thus, genetic privacy may be violated to ensure the viability of an insurance fund and to maintain actuarial fairness. In the context of education, a child's right to privacy may be violated by parents if a learning problem is suspected and a remedial program is available to assist the child. The genetic privacy of immigrants may be violated to protect public health, maintain the fiscal integrity of the health system and to avoid fraudulent claims of consanguinity and finally, in forensic investigations, the right of victims to justice and retribution and the collective right of society to safety and security trumps the privacy rights of suspects and criminals.

Whilst acknowledging that genetic privacy is not an absolute and inalienable right, protecting genetic privacy is an important goal for genetic policy. It is important for upholding the intrinsic value of preserving the integrity, dignity and autonomy of individuals and because it provides one of the most effective mechanisms for protecting against genetic discrimination.

Genetic Discrimination

Although the risk of social discrimination predates the genetics revolution, violations of genetic privacy give rise to a new expression of social discrimination in the form of genetic discrimination. As Murray suggests, genetic information broadens the pool of possible factors that may be used to discriminate against individuals and expands the pool of individuals who may be subjects of discrimination (Murray 1997).

Genetic discrimination has been defined as "the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests" (Gostin 1991). The risk of genetic discrimination arises in all the non-medical uses of genetic testing. Employers may make selective hiring, placement, promotion or termination decisions based on genetic profiling. Insurance companies may discriminate against asymptomatic or presymptomatic individuals when assessing eligibility and setting insurance premiums. Educators may discriminate against students diagnosed with a genetic condition that affects learning capability. Immigration officials may discriminate against the genetically disadvantaged when making immigration decisions, and the evidence based legal system may discriminate against individuals diagnosed with a genetic propensity to behave in a violent, aggressive or dishonest manner. The net social effect is likely to be the creation of a new social inequality and new social polarisation between the genetically advantaged and genetically disadvantaged. Ultimately, genetic discrimination will create an oppressed and marginalised genetic underclass, whose members are denied social rights and opportunities because of a genome they did not choose and cannot change (Mehlman and Botkin 1998).

The people most vulnerable to genetic discrimination are the people who are denied rights, privileges or opportunities because of genetic information that will not result in a future genetic disease. These include: individuals who are carriers of recessive or X-linked genes and who will remain asymptomatic; individuals with genetic conditions that can be treated before symptoms develop; individuals with mutations that make them susceptible to an illness but only if exposed to a specific environmental agent; parents of children whose condition was the result of a spontaneous mutation and untested and asymptomatic relatives of people diagnosed with a genetic condition.

Coercive or Compulsory Testing

The risk of coercive or compulsory testing is a third risk common to all the non-medical uses of genetic testing and indeed, the risk to genetic privacy and the risk of genetic discrimination intensify when testing is coercive or compulsory. To counter this problem, testing should always be performed with non-directive counselling and informed consent. Non-directive counselling is defined as a neutral mode of counselling that encourages the client to make the ultimate decision (Reed 1975). In reality, this ideal of testing with non-directive counselling and informed consent is difficult to achieve because it is often difficult to determine whether a person who consents to a genetic test is giving informed consent or passive consent or in some cases, whether consent was merely assumed because the person raised no objection. For example, people may give consent to a test they do not fully understand the significance of, or to which they have received inadequate, incomplete or inaccurate information. They may give their consent voluntarily, but without understanding the immediate and long term health, social and psychological consequences of the test result, this voluntary consent is not informed consent.

Furthermore, in situations of unequal power, people will often perceive testing as compulsory, whether or not the test was intended to be compulsory. In the context of employment for example, applicants will most likely perceive refusal to consent to the test as

jeopardizing their chance of being offered the job or promotion. In insurance, applicants will equate their refusal to be tested with a refusal by the insurance company to offer insurance. Parents may perceive failure to consent to a test offered by their child's school as jeopardizing their child's chance of academic success in that school. Applicants for immigration will most likely perceive failure to consent to a genetic test as placing their application at risk. Finally, the concept of voluntary testing with informed consent in forensic investigations is highly problematic because although suspects are given the option of giving a DNA sample voluntarily, if they refuse to cooperate a magistrate may order that a sample be taken without consent. The concept of non-coercive or consensual testing therefore seems superfluous when a suspect most likely perceives that if s/he withholds consent, the test will be ordered by the court.

To minimize the risk of coercive or compulsory testing, competent adults must sign a consent form. For incompetent adults and minors, this consent form must be signed by a legal guardian. The consent form should include information on why the test is being performed, how the test will be conducted, whether the result will be retained or destroyed and if retained, where the result will be stored, who will have access to the information and the potential consequences of the result for themselves and other family members. It should also explain to the individual that they have the right to refuse testing. The consent form should include the contact details of an independent agent who may be contacted if the individual believes they have been coerced, misled or deceived. Finally, the consent form should be easy to read, available in multiple languages, free from ambiguous statements and technical language and a duplicate must be given to the individual as a record.

Loss of Trust in the Regulatory Authorities that Govern Genetic Information

Former abuses of genetic testing, including coercive testing without counselling or consent, have led to a loss of trust in social authorities to keep genetic information confidential and a loss of trust in the regulatory authorities that govern the use of genetic information. This loss of trust in regulatory authorities is the fourth risk common to all the non-medical uses of genetic testing. Indeed, despite the many benefits of computer technology and information networks there is a risk to confidentiality arising from the electronic storage of genetic data (Alpert 2003). There is a risk that private information can be rapidly transferred from one agent to another and used for purposes other than that for which it was originally given. With a growing awareness of the ease with which electronic genetic information can be transferred between agents, individuals are increasingly reluctant to consent to any genetic test for fear the information will be accessed by a third party. Of particular concern is that individuals avoid genetic testing for health reasons because they fear the test results will be accessible by agents outside the medical sphere (Hall and Rich 2000; Kimberly, Quaid & Morris 1993).

Ironically, although more people fear unauthorized access to genetic data, it is often the authorized access to data in electronic files that presents the greater risk to individual privacy (Rothstein 1997b). Thus, policies must be designed to restrict authorised access and penalties imposed for individuals who abuse their authorised access.

Misunderstanding, Misinterpretation or Overestimating the Information Obtained from Genetic Tests

With all uses of genetic testing in the clinical, research or non-medical sphere, there is a risk of misunderstanding, misinterpretation or overestimating the information obtained. Thus, the test itself is benign, but the analysis of the results can be harmful. One of the most common

errors is misunderstanding that genetic tests only reveal a probability not a certainty and hence, misunderstanding that although a gene mutation may indicate that an individual is at a higher risk of developing a certain disease, it does not reveal the severity of the disease or the time of onset. Other areas of misunderstanding include: misunderstanding the difference between genotype and phenotype, or between having a gene and having a disease; misunderstanding the difference between dominant and recessive alleles and hence, the meaning of carrier status; misunderstanding the difference between monogenic, polygenic and multifactorial diseases, meaning the difference between diseases caused by single genes, many genes or by a combination of genes and the environment; misunderstanding the meaning of essential concepts such as penetrance and variable expressivity; and finally, misunderstanding the distinction between what is currently possible and what is future speculation.

Overestimating the predictive value of genetic tests is a common error and one of the major errors contributing to genetic discrimination. Overestimating the predictive power of genes is synonymous with the concepts of genetic determinism, genetic reductionism, genetic essentialism and genetic fatalism. These concepts are misleading because they ignore the role the social and physical environment play in the aetiology of all disease and the expression of all human traits. Employers who subscribe to the notion of genetic determinism will be more likely to discriminate against asymptomatic individuals with a genetic mutation. Insurance assessors that reduce human disease to single genes will be more inclined to introduce genetic testing and to adjust premiums based on genetic results. Educators seduced by the simplicity of genetic explanations may explain academic failure as genetic fatalism rather than attempt to improve teaching methods and create an environment that will inspire, encourage and reward effort and achievement. Basing immigration decisions on genotype will inevitably result in the denial of life opportunities for many individuals. Finally, the use of genetic testing to identify individuals who are genetically programmed to engage in criminal or anti-social behaviour is risky because of the potential that crime will be viewed as a pathology of the individual rather than an outcome of social factors and because of the risk that crime prevention policies will be oriented towards changing the behaviour of individuals rather than changing the exogenous social environment that continuously and cumulatively shape social behaviour.

One option for alleviating this problem of misunderstanding the information revealed by genetic tests is to invest in programs for raising the public understanding of gene technology in general and genetic testing in particular. Indeed, eliminating some of the myths of gene technology and changing negative social attitudes towards people living with gene mutations, may be a more effective policy against genetic discrimination than anti-discrimination legislation (Powers 1997).

Options for promoting the public awareness and understanding of genetic testing include sponsoring public lectures and seminars, producing information booklets for distribution in public areas, developing genetic awareness programs in primary and secondary schools, establishing informative and interactive web sites, increasing the quality, quantity, accuracy and objectivity of media reports on gene technology and conducting occasional consensus conferences and citizen's juries that deliberate on specific applications of gene technology.

These options for raising the public understanding of gene technology are informed by models of deliberative and participatory democracy. The model of deliberative democracy is based on the idea that the public should be encouraged to deliberate on the ethical, legal, social and political implications of genetics, while the model of participatory democracy is based on the idea that members of the public must be given the opportunity to participate in

decisions that affect their own lives and the lives of future generations. Both models are based on the premise that as individuals acquire more knowledge about the procedural and substantive issues surrounding genetic testing, they will acquire more power to make rational choices about their own use of genetic testing and furthermore, as individuals acquire more knowledge about gene technology, they will be less vulnerable to the harmful and often insidious effects of genetic surveillance and genetic discrimination.

One of the major problems with privacy laws and anti-discrimination legislation is that individuals must be aware that the laws exist and aware of the processes through which these laws may be accessed. These outreach programs for raising the public understanding of genetic tests should therefore include information for raising awareness of the existence of these laws, the processes for accessing these laws and for making people more familiar with the independent regulatory authorities that govern genetic testing.

Using Gene Technology as an Instrument of Social Surveillance rather than as a Tool for Empowering Individuals

Finally, common to all the non-medical uses of genetic testing is the risk that gene technology will be used as an instrument of social surveillance rather than a tool for empowering individuals. The original aim of genetic testing was to provide individuals with information that would be advantageous for medical treatment or prophylactic lifestyle changes. This was informed by the view that knowledge is power and thus, an increase in genetic knowledge gives the individual greater power over their body and future. When genetic tests are used by social authorities such as employers, insurance assessors, educators, immigration officials or law enforcement agencies, there is a risk that genetic knowledge is being misused as a form of social power over individuals and hence, the enabling power of genetic testing for individuals become a repressive, oppressive or restrictive power over individuals. Genetic testing becomes an instrument for classifying and categorising individuals, for creating boundaries of social inclusion or exclusion, for creating a new social inequality and polarization between the genetically advantaged and genetically disadvantaged and for establishing greater surveillance over bodies. This is the antithesis of the original expectation of using genetic testing as an instrument for liberating individuals from the burden of genetic uncertainty and genetic disease.

Conclusion

Initially designed for medical diagnostics, genetic tests are increasingly used by agents outside the medical sphere and for reasons other than providing health advice or treatment. While every application of genetic testing raises a number of unique risks there are several common risks that emerge from the use of genetic testing by employers, insurance companies, educators, immigration officials and law enforcement officials. Identifying these common risks is an essential starting point for developing risk avoidance and risk management policies. This paper makes a number of recommendations for the socially responsible use of genetic testing. These recommendations do not include the option of a total prohibition on the use of genetic testing, nor the option of prohibiting further research on developing genetic testing, because to prohibit genetic testing would be to deny individuals, institutions and society the many benefits. The challenge is to develop sustainable policies that will maximize the benefits and minimise the risks rather than eliminate both.

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