Ethics and Genetics: Susceptibility Testing in the Workplace[1]

Chris MacDonald
Bryn Williams-Jones[2]

ABSTRACT. Genetic testing in the workplace is a technology both full of promise and fraught with ethical peril. Though not yet common, it is likely to become increasingly so. We survey the key arguments in favour of such testing, along with the most significant ethical worries. We further propose a set of pragmatic criteria, which, if met, would make it permissible for employers to offer (but not to require) workplace genetic testing.

KEY WORDS: genetic testing, privacy, workplace health and safety, workplace screening

Introduction

The rapid advances made in genetic research and technology over the last few decades have led to a host of important advances in the detection (and hopefully soon the treatment) of genetic conditions and diseases. These developments have also raised ethical concerns about how resulting technologies will be implemented, and about how their implementation will impact different communities. One particular set of concerns surrounds the use of genetic testing in the workplace. Though not yet common, workplace genetic testing is bound to become a real option for employers as genetic technologies improve.[3]

Genetic testing comes in two forms: screening and monitoring. Genetic *monitoring* (which tends to be supported by labour advocates) detects genetic abnormalities potentially caused by exposure to workplace toxins: an alert to hazards in the workplace, similar in principle to radiation detection badges. By contrast, genetic *screening* (the focus of this paper), is used to detect hereditary disease or susceptibility to workplace toxins. This could be used for pre-employment testing, employee placement, and risk avoidance – all useful tools for employers (Department of Labor et al., 1998).

What can be screened for and why?

Genetic screening can be used to detect which individuals have a genetic makeup associated with particular hereditary diseases, such as sickle cell anaemia, cystic fibrosis, and Huntington disease. Screening can also detect genes that confer increased susceptibility to workplace toxins or environmental factors, e.g., N-acetyltransferase phenotype (increased risk of bladder cancer in those exposed to carcinogenic arylamines (Vineis and Schulte, 1995)), or Glu-69 (heightened susceptibility to beryllium, which can cause pulmonary disease (American Nuclear Society Environmental Sciences Division, 1998)).[4]

Employers might benefit from genetic screening through reduction in costs associated with occupational disease, e.g., lost productivity, excess absenteeism, worker's compensation

---

Chris MacDonald is a Bioethicist in the Department of Bioethics at Dalhousie University. His research interests span across moral theory, bioethics, business ethics, and professional ethics. Dr. MacDonald's research is currently focused on issues of business ethics and professional ethics as they apply to the field of biotechnology.
Bryn Williams-Jones is a Doctoral Candidate and Graduate Research Associate at the Centre for Applied Ethics, University of British Columbia. His research focuses on genetics, ethics and commercialization. He is particularly interested in the social, ethical, and policy implications of the commercialization of genomic and genetic technologies.

Journal of Business Ethics **35**: 235–241, 2002.

payments, health insurance premiums, and legal liability (Andre and Velasquez, 1991). While some tests are still relatively expensive, they will become more affordable as technologies develop (e.g., DNA chips, cf. Wickelgren, 1998), and through cost savings from maintaining a healthy workforce. A further argument in favour of genetic screening is that in order to maintain a healthy and productive workforce and safeguard corporate interests, companies have to be selective about who they hire or retain as employees. It can be argued that companies are not unfairly discriminatory in selecting against employees at risk for hereditary disease or genetic susceptibility. Workplace discrimination is generally not thought to be unfair if the issue is a "bona fide" requirement of the job. And it may simply not be economically feasible for the employer to eliminate all substances that put a few hypersensitive employees at risk. It may be more sensible, from an economic point of view, not to hire susceptible workers or to transfer susceptible workers to different positions. Finally, if challenged that using genetic screening in the workplace is unfairly discriminatory, employers can reply that prospective (and current) employees do not have a right to work at a specific company, and that those who object to screening can seek employment elsewhere. Of course, this reply is plausible only while workplace genetic testing remains rare – if it becomes common practice, some people may become unemployable because of genetic susceptibility.

It can also be argued that workplace genetic screening will benefit both workers and employers by helping to maintain a healthy workforce. Employers have a general ethical obligation to minimize the likelihood of workplace illness and injury. One way to approach this obligation is to improve the workplace – that is, to tailor the workplace to needs of the worker. But, since workplace illness and injury typically involve interaction between some characteristic of the workplace and some characteristic of the worker, another way to approach this obligation is to tailor the worker to the workplace. If the latter approach is taken, it will generally mean not modifying particular workers, but changing which workers have which jobs. That is, it will mean avoiding placing workers into work environments that, because of particular characteristics of those workers, are particularly dangerous to them. This was the rationale for DuPont's voluntary sickle cell anaemia screening program in the 1970s, and for the widespread restrictions in the chemical industry that preclude women from working in environments that expose them to chemicals known to cause birth defects (cf. Draper, 1991).

Screening may also benefit workers directly by providing information that will allow them to avoid placement in potentially harmful environments, thereby sparing workers and their families the physical, emotional, and financial burdens of disabling disease or premature death. The suggestion is that, once informed of their increased risk, workers can evaluate their situation and take voluntary preventative measures to avoid exposure.

Opposition to workplace screening

The above arguments in favour of genetic screening will be unsatisfactory to many. Screening, it may be argued, is unjustly discriminatory, is a threat to privacy, offers only a questionable degree of accuracy, and does not ensure a safe working environment. On these grounds, some will argue that genetic screening should be restricted.[5]

Justice requires people be treated equally unless there are *relevant reasons* for different treatment. Differences in skill, knowledge or experience would be relevant criteria for hiring or placement. However, traits that are not within the control of the individual, such as gender, ethnicity, or disability, are commonly held (e.g., in the Canadian *Charter of Rights and Freedoms*, and the U.S. *Americans with Disabilities Act*) to be unjust grounds for discrimination. Thus it has been argued that one's genetic makeup, like disability, should not be reason for discrimination (cf. Annas, Glantz et al., 1995; Task Force on Genetic Information and Insurance, 1993; Murray et al., 2001). Further, given that predispositions to genetic diseases may be associated with specific ethnic backgrounds (e.g., sickle cell anaemia in people of African descent or Tay-Sacks disease in Ashkenazi Jews) there is concern that screening could stigmatize and negatively impact historically disadvantaged groups (cf. Task Force on Genetic Information and Insurance, 1993).

The usefulness and scientific validity of workplace genetic screening have also been challenged (Draper, 1991; Department of Labor et al., 1998). Screening is not diagnostic, but predicts only *risk* or *susceptibility*. The information provided by means of genetic testing will not determine whether a person will *in fact* develop a condition, only that they are more *likely* to do so than others.[6] Moreover, there are problems with the sensitivity and specificity of the screening methods – a test may be accurate but still miss people who are at risk (a "false negative"), or on the other hand, label some people as at increased risk who are not actually susceptible (a "false positive"), thereby increasing anxiety and possibly resulting in the unwarranted termination of a position. To be "at risk" implies a *probability* of developing a condition that *might* affect performance – even with a positive result on a test, a person might never develop the condition. Nor does being at risk directly affect current ability to perform, except to the extent that this information creates fear and anxiety, which could affect a person's performance. Confidence in genetic screening may also be unreasonable given the complexity of the human genome and the complexity of its interaction with the environment (Lewontin, 2000). Most of the conditions that would likely be of interest for workplace testing are mutlifactorial, i.e., there are numerous factors involved in the development of disease, only some of which are genetic. And even when there is an association between a specific gene and development of disease, there may be other (unknown) genetic factors necessary before the target gene gets "turned on" and causes cancer, for example. Thus a person who tests positive for "the gene" in question may still never develop the disease (Baird, 2001).

There is also concern that genetic screening will lead to employees not being treated as individuals, but as "risk groups" who are in some way to blame for their conditions, thereby distracting from the responsibility borne by the company for workplace safety – employers should be improving safety and removing hazards, not shifting responsibility to employees (Kegley, 1998).[7]

Given that the gap between diagnosis and treatment is still great for most genetic disorders, screening will likely be of dubious direct medical benefit to employees. Even if an employee is found to be at risk, the best that can be offered is transfer to a different position and increased monitoring. But genetic information can be a significant psychological and social burden, especially if one is told one has "a defective gene" or is "at risk." Such news might affect a person's conception of health and identity,[8] lead to stigmatization, or even make a person unemployable or uninsurable. (Such risks might be mitigated through genetic counselling, but counselling is unlikely to eliminate such risks altogether.) For these reasons, it is widely argued that genetic information should be treated as personal and private,[9] and that access by third parties should require convincing justification (Secretary's Advisory Committee on Genetic Testing, 1999). Forcing an employee to undergo genetic screening also forces the employee to deal with the resulting information, and studies on the psychological impact of genetic testing have shown that it may sometimes be better "not to know" (Benjamin et al., 1994; Codori, 1997; Cox and McKellin, 1999).

Is there room for compromise?

Those in favour of genetic screening are probably justified in citing employee benefit, corporate responsibility, and economics as reasons for using genetic testing to select against certain employees while protecting those already employed who may be susceptible. Opponents to screening also provide persuasive arguments for the need for concern about justice and discrimination, scientific validity, and privacy. There are further concerns, particularly in the U.S., regarding risks to employees' insurability (for both health care and life insurance) (Murray et al., 2001). While we find the arguments against screening at this time are in general more persuasive (given the rather low accuracy of testing, the low utility of risk information, and the clear potential for injustice and discrimination), screening may be a viable option – both technically and ethically – in certain specifiable situations either now or in the future. Obviously the accuracy of testing methods must be improved, but more importantly, testing must be administered in a just and respectful manner.

Given that workplace genetic testing is a technology both full of promise and fraught with ethical peril, we suggest a pragmatic approach that allows for the possibility of workplace genetic testing, but that attempts to minimize its negative effects. Each of the positive and negative factors alluded to above warrants serious ethical investigation. Such work has begun, but is far from adequate to provide satisfying answers. In the meantime, we propose a set of criteria, the satisfaction of which would make it *prima facie* permissible for employers to offer genetic testing to workers. *Requiring* workers to submit to genetic testing is significantly more problematic morally. Forced testing would constitute an invasion of privacy, and expose the worker – on a non-voluntary basis – to a range of poorly understood risks. Thus it may not be possible to identify circumstances in which such a requirement would be ethically permissible. We do not attempt that task here. As a result, we restrict our discussion to the search for conditions under which it would be permissible for employers to offer employees the *opportunity* to be tested.[10] We contend that it is *ethically permissible* to offer genetic testing to employees if the following six conditions are met:

1. A genetic test (for a specific condition) must be available which is highly specific and sensitive and offers an acceptably low incidence of both false positives and false negatives; such a test must test for a gene that is sufficiently penetrant for the test result to have some important health implication.
2. Testing should be carried out by an independent lab, and results of genetic tests should be given to workers directly, either by a geneticist or a genetic counsellor; test results should be held confidential, and revealed to the employer only at the employee's request;
3. Pre- and post-test genetic counselling must be available from a qualified health professional, and paid for by the employer, regardless of the outcome of the test;
4. The gene being tested for must not be prominently associated with an identifiable and historically disadvantaged group;
5. Where relevant, the employer must guarantee continued access to group insurance;
6. The employer must ensure that if the employee chooses to reveal that she has tested positive, suitable policies are in place to ensure a reasonable degree[11] of job security.

We feel that if the above criteria were met, it would be ethically permissible to offer (but not to *require*) workplace genetic testing. Meeting these criteria would allow employers to offer genetic testing, and further to have reasonable answers in the face of most of the objections noted above. The only concern *not* directly addressed by meeting these six criteria is the worry that, in focusing on tailoring the workforce to the workplace environment (by using genetic testing to weed out those workers who are particularly susceptible to workplace hazards) employers may neglect improvements to the workplace that would benefit *all* employees. It would of course be possible to further stipulate that, in order for it to be permissible to offer genetic testing, employers must also ensure that other appropriate measures are taken to clean up the workplace so that the interests of "normal" workers as well as "at risk" workers are served. We feel, however, that the obligation to provide a safe workplace for all employees is a general issue that can be separated from the issue of genetic testing.

If the six criteria above are met, then any genetic test that is offered holds the promise of being good for all involved. The employer reduces costs associated with employee illness; at-risk employees gain the information needed to remove themselves from work environments that pose special risks for them; and employees found *not* to be at increased risk gain the comfort of that knowledge. These advantages (in the absence of the disadvantages avoided through meeting our six criteria) justify offering testing. They do not justify failure to maintain a reasonably safe environment for all employees: employees found not to be at risk gain only psychological comfort from testing, and untested employees gain nothing at all from testing. The availability of testing does little if anything to change employers' health-and-safety related obligations to these employees.

Next, let us ask, is it ever ethically *mandatory* for employers to offer genetic testing? We believe that it is, and suggest that it be considered mandatory for an employer to offer genetic testing to employees if conditions 1 through 6 above are satisfied, and if, in addition, the following conditions are met:

1. Knowing their status with regard to the genetic characteristic in question can reasonably be expected to influence at least some employees' decision to remain in their current position;
2. The cost of the test is "reasonable" (e.g., is similar to the costs of other insured medical services, or other normal workplace benefits).

We think that the possibility of an obligation to offer testing to employees – and the financial burden that would imply – goes hand in hand with the possibility of *offering* genetic testing to employees, and the risks such testing would imply for them.[12] In considering whether they favour a world in which employees *may* be tested, employers should also consider whether they also favour a world in which they may be *obligated* to offer testing.

The future is likely to see a rapid expansion in the number of genetic conditions or susceptibilities that can be tested for, and testing will become cheaper, more accurate, and more widely available (Silverman, 1995; Secretary's Advisory Committee on Genetic Testing, 1999; Williams-Jones, 1999). This could provide for better monitoring and screening of employees to increase safety, but only if both the motivation and the process are fair and non-discriminatory. Given the often restrictive nature of many governmental responses to developments in genetic research and technology (e.g., the response to fetal cell research, cloning, etc.), screening tests will almost certainly be restricted unless they are proven scientifically valid and used in a just and equitable manner. Genetic technologies are becoming increasingly important in our lives – something that is not soon likely to change. Careful thought needs to go into the conditions under which such technologies should be welcomed into our lives.

Notes

[1] Authorship of this paper is shared equally. The authors wish to thank Charles Weijer, Susan M. Cox, Jason Scott Robert, and Paul Miller for helpful comments on various drafts. Many of the ideas here have also benefited from ongoing critique and discussion with the Genetics and Ethics Research Group at the UBC Centre for Applied Ethics.

[2] Bryn Williams-Jones's research is supported in part by The Canadian Health Services Research Foundation (CHSRF), the Social Sciences and Humanities Research Council (SSHRC), and the Faculty of Graduate Studies and Centre for Applied Ethics at UBC.

[3] For a review of some of the forms of genetic testing currently becoming commercially available (and the social, ethical and policy implications of these developments), see (Williams-Jones, 1999; Burgess, 1999).

[4] We refer here primarily to laboratory tests indicating the presence of a particular gene. Similar information can sometimes be acquired simply by means of taking a family history, when the inheritance characteristics of a particular gene are known. For example, since the gene for Huntington disease is dominant, an individual whose family history includes a parent with the disease would have, based on family history alone, a 50% chance of inheriting the gene (and thus of manifesting the disease), while their children would in turn be at 25% risk. Some of the worries about genetic testing thus should also apply to the gathering of family histories.

[5] The scenario in which workplace genetic testing is carried out in an oppressive manner is exemplified in the 1997 science fiction movie, "Gattaca." But not

all examples come from science fiction. In 1970, a test was developed to screen for carriers of sickle cell trait, a recessive genetic condition that causes a severe form of anemia, and affects 1 in 500 African Americans. The U.S. Air Force used this test to refuse African-Americans with this trait from becoming pilots. The Air Force was afraid that reduced oxygen levels in cockpits would trigger the disease. However, this recessive condition only occurs in individuals who have both copies of the faulty gene (and will thus have a history of disease) as opposed to carriers who have one copy, but are unaffected (those the test was picking up). This test was used as justification to discriminate against a group of people, who would never actually develop the condition. The Air Force ended its sickle cell screening program in 1981 (Draper, 1991). More recently, The Burlington Northern & Santa Fe Railroad Co. was sued (for violating the Americans with Disabilities Act) by the U.S. Equal Employment Opportunity Commission, on behalf of the employee union, for obtaining blood samples and conducting genetic testing on employees claiming work-related carpal tunnel syndrome (Ceniceros, 2001).

[6] There are rare exceptions, such as the test for Huntington disease. Individuals who test positive for the expanded number of tri-nucleotide repeats associated with HD have (nearly) a 100% chance of developing this degenerative neurological disorder at some point in their lives. (Such a gene is called "highly penetrant" by geneticists.) It would be too easy to be misled, by examples like Huntington disease, into thinking that genetic tests usually provide certainty.

[7] As Trudo Lemmens has noted (1997, p. 60), the focus on genetic susceptibility ignores the fact that workers who do not have the gene associated with *increased* susceptibility to some hazard can nonetheless still be affected by that hazard. Focusing on genetic screening obscures the needs of "normal" workers.

[8] We might reasonably wonder, of course, whether the impact of genetic testing is different in this regard from the impact of, for example, intelligence testing.

[9] Note that the possibility of misinterpretation of genetic information may be a greater threat than simple lack of control over personal information.

[10] Some will wonder why we need justification even to *offer* testing; that is, they will wonder why employees' consent to being tested is not sufficient. The answer lies primarily in the possibility that a) the offer may in some sense be coercive; and b) employees may not in all cases understand the ramifications of consenting to be tested. As a parallel, note that consent is not always considered sufficient to justify subjecting patients to medical research. See (Weijer et al., 1997).

[11] Just what would constitute a "reasonable" degree of job security is an important question; an employer's justification in offering genetic testing would depend, in part, upon justifying suitably the degree of job security that was ensured.

[12] In a similar vein, Lemmens (1997, p. 70) argues that when reliable genetic *monitoring* is available, providing such monitoring should be considered obligatory.

References

American Nuclear Society Environmental Sciences Division: 1998, *Proceedings of the Topical Meeting on Risk-Based Performance Assessment and Decision Making* (Richland/Pasco, WA).

Andre, Claire and Manuel Velasquez: 1991, 'Read My Genes: Genetic Screening in the Workplace', *Issues in Ethics* **4**(2), <http://scuish.scu.edu/Ethics/publications/iie/v4n2/genes.shtml>.

Annas, George J., Leonard H. Glantz and Patricia A. Roche: 2000, *The Genetic Privacy Act and Commentary*. Human Genome Project Information 1995 [cited 25 July 2000]. <http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html>.

Baird, Patricia A.: 2001, 'Will Genetics Be Used Wisely?' *ISUMA: Canadian Journal of Policy Research* **2**(1), 94–101.

Benjamin, C., Adam S., S. Wiggins and et al.: 1994, 'Proceed with Care: Direct Predictive Testing for Huntington Disease', *American Journal of Medical Genetics* **55**, 606–617.

Burgess, Michael M.: 1999, 'Marketing and Fear-Mongering: Is It Time for Commercialized Genetic Testing?', in T. A. Caulfield and B. Williams-Jones (eds.), *The Commercialization of Genetics Research: Ethical, Legal, and Policy Issues* (Kluwer Academic/Plenum Publishers, New York, NY).

Ceniceros, Roberto: 2001, 'Genetic Screening Faces Lawsuits', *Business Insurance* **35**(8), 1, 42.

Codori, A.-M.: 1997, 'Psychological Opportunities and Hazards in Predictive Genetic Testing for Cancer Risk', *Colorectal Neoplasia, Part II: Diagnosis & Treatment* **26**(1), 19–39.

Cox, Susan M. and William McKellin: 1999, '"There's This Thing in Our Family": Predictive Testing and the Construction of Risk for

Huntington Disease', *Sociology of Health & Illness* **21**(5), 622–646.

Department of Labor, Department of Health and Human Services, Equal Opportunity Commission, and Department of Justice: 1998, 'Genetic Information and the Workplace' (Department of Labor, U.S. Government, Washington, DC).

Draper, Elaine: 1991, *Risky Business: Genetic Testing and Exclusionary Practices in the Workplace* (Cambridge University Press, Cambridge).

Kegley, Jacquelyn Ann K.: 1998, 'Genetic Information and Genetic Essentialism: Will We Betray Science, the Individual, and the Community', in J. A. K. Kegley (ed.), *Genetic Knowledge: Human Values & Responsibility* (International Conference on the Unity of the Sciences, Lexington, KT).

Lemmens, Trudo: 1997, '"What About Your Genes?" Ethical, Legal and Policy Dimensions of Genetics in the Workplace', *Politics and the Life Sciences* **16**(1), 57–75.

Lewontin, Richard C.: 2000, *The Triple Helix: Gene, Organism, and Environment* (Harvard University Press, Cambridge, MA).

Murray, William D., James C. Wimbush and Dan R. Dalton: 2001, 'Genetic Screening in the Workplace: Legislative and Ethical Implications', *Journal of Business Ethics* **29**(4), 365–378.

Secretary's Advisory Committee on Genetic Testing (SACGT): 1999, 'A Public Consultation on Oversight of Genetic Tests', *Federal Register* **64** (67273), <http://www4.od.nih.gov/oba/sacgt12-99.htm>.

Silverman, Paul H.: 1995, 'Commerce and Genetic Diagnostics', *Hastings Center Report* **25**(3), S15–S18.

Task Force on Genetic Information and Insurance: 1993, 'Genetic Information and Health Insurance: Report of the Task Force on Genetic Information and Health Insurance' (National Institutes of Health, Washington, DC).

Vineis, Paolo and Paul A. Schulte: 1995, 'Scientific and Ethical Aspects of Genetic Screening of Workers for Cancer Risk: The Case of N-Acetyltransferase Phenotype', *Journal of Clinical Epidemiology* **48**(2), 189–197.

Weijer, Charles, Bernard Dickens and Eric Meslin: 1997, 'Bioethics for Clinicians 10: Research Ethics', *CMAJ* **156**(8), 1153–1157.

Wickelgren, I.: 1998, 'Gene Readers', *Popular Science* (Nov.), 56–61.

Williams-Jones, Bryn: 1999, 'Re-Framing the Discussion: Commercial Genetic Testing in Canada', *Health Law Journal* **7**, 49–68.

Chris MacDonald
Department of Bioethics,
Dalhousie University,
Canada

Bryn Williams-Jones
Centre for Applied Ethics,
University of British Columbia
Canada