IMPLICATIONS OF GENETIC TESTING FOR THE WORKPLACE AND ACC

Findings from interviews by the Complementary Expertise Sub-team

Research Report no. 8
June 2005

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Biotechnologies, dialogue and informed decision-making

A research project funded by FRST
The Foundation for Research, Science and Technology
Abstract

This report discusses the findings of a research project that investigated the social implications of genetic testing in the areas of employment and ACC. The project was designed to elicit knowledge of social practices most likely to shape or be shaped by genetic testing. The research suggests that while genetic testing is not a current focus of attention among employers, unions or ACC, there are incentives and opportunities to use it in the future, particularly in relation to work involving exposure to toxic substances, injury-prevention strategies, and claims involving ‘work-related gradual process, disease or infection.’ Current practices within the employment-relations and ACC arenas that may influence the possibility and implications of utilising genetic testing are identified. Access to and handling of personal information emerges as an important issue, as does the role of power inequalities in exacerbating the negative implications of genetic testing. The report concludes that both explicit policy action and wide-ranging societal debate are needed in this area.

Acknowledgements

This Constructive Conversations/Whakaaetanga Korero research project is funded by the Foundation for Research, Science and Technology research grant to the University of Canterbury (UOCX0221). The programme leader for 2003-2005 is Rosemary Du Plessis. The ‘Complementary Expertise’ Sub-team for the research on genetic testing consisted of Joanna Goven, Jane Gilbert and Fiona Cram.

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1. Introduction

Understanding whether and/or how a technology should be developed, permitted or regulated requires knowledge both of ‘technical’ attributes of the technology and of the nature of social practices with which it will interact and in which it will be embedded. Knowledge of social practices is largely experiential: what is relevant are not abstractions, generalisations or formal rules, but actual (often adaptive, innovative, constrained or ‘deviant’) practices. Of course, formal rules influence social practice, but the two are not equatable. Yet while knowledge of formal rules (legislation, codes, standards, recommended practices) often contributes to policy-making in relation to a technology, experiential knowledge of relevant social practices typically does not.

Here I report on the findings from a subproject within the Constructive Conversations/Whakaaetanga Korero Research Programme that was specifically designed to elicit knowledge of a particular range of social practices most likely to shape or be shaped by genetic testing. This work began in March 2004. It trialled an approach that will be applied to a longer-term study of biopharming, beginning in July 2005.

The approach involved identifying likely concentrations of social knowledge relevant to genetic testing and eliciting the expression of that knowledge by those who may not immediately recognise its relevance to the issue at hand. It began with the conventional research skills of locating and analysing related research in a scoping exercise to identify some of the areas of social practice likely to be relevant to understanding the implications of genetic testing for New Zealand. Having identified these areas, we (the researchers) then determined which individuals or groups are most likely to have a store of extensive, detailed and experiential knowledge of each of these areas of social practice.

A challenge of the method is to enable the interview participants to identify the knowledge they have (and we don’t) that is relevant to the subject we have chosen to investigate, particularly when the subject has not yet entered the public arena in a significant way. Thus the next step was to develop ‘translational’ materials that gave digestible background information on genetic testing as well as an indication of why their knowledge may be relevant.

The implications of genetic testing have been canvassed in a number of reports across a range of OECD jurisdictions; some of the more recent among them include: Australian Law Reform Commission (2003a and 2003b), Ontario Provincial Advisory Committee on New Predictive Genetic Technologies (2001), U.S. National Institutes of Health Advisory Committee on Genetic Testing (2000), Gene Watch UK (2002), UK Human Genetics Commission (2002 and 2003), European Group on Ethics in Science and

A major theme emerging from the work cited above is the potential for discrimination in employment and insurance. As formal rules and practices in employment and insurance differ in New Zealand from those in the jurisdictions where existing investigations into these areas have been carried out, we elected to focus in the first instance on the implications of genetic testing for employment relations, employment-related insurance, and workplace issues more generally.

Our research had indicated that in other jurisdictions it is expected that employers will increasingly come under pressure from insurance companies (where employment is linked to health, life, or disability insurance) or workers’ compensation schemes (directly or through the cost of premiums) to use genetic tests to screen employees and/or potential employees (European Group on Ethics in Science and New Technologies 2003; Australian Law Reform Commission 2003a). Screening may also arise in relation to pension and early retirement schemes (UK Human Genetics Commission 2002).

Employment law and practices and insurance arrangements are not the same in New Zealand as they are in, for example, the US or the UK. Different social practices and starting points may result in different sets of implications and may call for different policy responses. Our task was therefore to identify sources of knowledge of these practices.

While virtually all employers and employees, drawing on their own experience, have some knowledge of workplace practices, we looked for individuals who would have accumulated knowledge of a range of experiences in this area. In this group we initially included trade union and employers’ association representatives as well as employment lawyers. Our interviews threw up two immediate findings: 1/ genetic testing has not yet become a focus of attention in the employment-relations arena in New Zealand; and 2/ the Accident Compensation Corporation (ACC), unique to New Zealand, is likely to be a significant area of practice in relation to genetic testing.

ACC is meant to provide compensation and rehabilitation, on a no-fault basis, for workplace accidents and ‘personal injury caused by work-related gradual process, disease, or infection’; it does not provide compensation or rehabilitation for injuries due to ‘natural degeneration’ and other non-work-related processes. (It does cover accidents, regardless of whether they occur at work). Whether a person’s condition falls into the compensated or uncompensated categories can be a point of contention between ACC and its claimants.
The potential uses of genetic testing in relation to workplace accident and illness, the importance of ACC in the insurance field in New Zealand, and New Zealand’s distinctiveness from other jurisdictions in this regard argued for a strong focus on ACC within our project. This required, in addition to a scoping of ACC practices and issues, further research into those aspects of genetic testing likely to be particularly relevant to ACC. One of these areas is the development of genotoxicological testing.

Genetic tests produced through toxicogenomic research target pre-existing genetic variation associated with greater or lesser susceptibility to harm from exposure to known toxins. They could potentially be accessed by employees or claimants to argue for a link between their illness and exposure. It has also been suggested that tests could be required by employers or insurers, with two seemingly contradictory possible outcomes: on the one hand, a negative result could potentially be used to argue against a link between the workplace toxin and the illness, or to argue that the employee is not likely to have a particular illness, as in the case of illnesses without definitive symptoms, such as occupational overuse syndrome or some neurotoxicological disorders; on the other hand, a positive result (for this and/or other mutations) could potentially be used to argue that the affected person’s disease was caused to a legally significant extent by genetic predisposition rather than exposure to the toxin (see Marchant 2000).

Toxicogenomic researchers are also focused on producing genetic tests that look for certain genetic changes (‘biomarkers’) characteristic of those who have been exposed to certain substances. In some cases, there are genetic changes that are interpreted as indicating (merely) exposure and further changes interpreted as indicating ill-effect. Attempts have been made in ‘toxic tort’ court cases in the US to use such tests to argue that an illness has been (or could not have been) caused by exposure to a particular hazard; the use of genetic tests in this way may increase significantly in the future (see, e.g., Eaton 2004; Grodsky 2005; Henry 2002).

As with private insurance companies, disputes have arisen between ACC and claimants over the nature and causation of injury. This is particularly the case in relation to musculo-skeletal disorders and illness related to exposure to workplace toxins. What are the social implications of the use of genetic testing in such disputes? Are there institutional or social forces or legal protections influencing this possibility? What can be learned with regard to this from current ACC practices?

Some of these questions can be answered, at least in part, from official sources, while others cannot. Here it is worth noting again that actual practice is at least as relevant as formal rules. Relevant social knowledge in this area comes in the form of, e.g., knowledge
of practice, of claimant experience, and of institutional culture, as well as of legislation and judicial decisions.

It is important to clarify at this point that we are not researching ‘public opinion’ on ACC or evaluating its performance. The majority of ACC claimants may well have had satisfactory interactions with ACC. Conducting a survey of ACC claimants, or a sample thereof, would be useful if our goal were to evaluate ACC performance. However, it is not particularly helpful to an exploration of how genetic testing may impact upon ACC practice. This deserves further explanation.

Concerns raised elsewhere with regard to genetic testing are often related to what have been, or would be initially at least, ‘marginal’ practices: for example, the exclusion from employment or insurance of the small numbers of people affected by currently available tests, the unsanctioned use of genetic data, or the selection of ‘superbabies’ by some wealthy couples. In one sense, marginal practices should concern us because they may signal something that will in the future become much more general. In another sense, marginal practices should concern us because they may be affecting exactly those most vulnerable people whom we have the greatest obligation to protect. For this reason, we have explored some of the most contested and contentious areas of ACC practice. Additionally, the question of whether genetic testing is likely to exacerbate or meliorate existing problems and tensions in ACC practice is an important one from a policy perspective.

With that in mind, in addition to our interviews with union and employer’s association representatives and employment lawyers, we have sought to explore the implications of genetic testing for employment and workers’ compensation with members of ACC-claimant and occupational-injury support groups, lawyers who undertake ACC cases, and occupational health researchers and practitioners (some of whom work within ACC). What follows is a discussion of the major themes from our discussions.

2. Employment

Genetic testing is not yet recognised as an employment-relations issue in New Zealand

We approached a number of representatives of major unions and employers’ organisations, as well as employment lawyers, for interviews. The biggest barrier to obtaining interviews was a belief that genetic testing had no relevance to their work. Those who did agree to be interviewed all expressed a version of ‘As far as I know, no one is using or discussing using genetic testing in relation to employment in New Zealand at this time.’ Yet, by the end of the interview, virtually all had noted a potential for
genetic testing to be used in relation to employment in New Zealand. As one union representative put it: ‘[I]f it becomes cheap enough and easy enough to do it, somebody will want to do it, there’s no doubt about that. I’d like to think that we … would get some advance warning of that happening.’

A number of participants referred us to legislation that they thought would prevent or discourage the use of genetic testing in relation to employment, in particular, the Human Rights Act (1993). According to a representative of an employers’ association, during the hiring process ‘employers tend to be pretty careful about what they ask, to the extent that some just won’t ask medical questions because they are a little bit worried about that information being used in terms of a Human Rights action.’

However, it was also pointed out to us by those associated with both unions and employers that there is ambiguity around those Human Rights Act provisions, especially where they intersect with the Health and Safety in Employment Act (1992). Section 22 of the Human Rights Act comprehensively prohibits discrimination in employment on specified grounds. These grounds include disability, which in turn includes inter alia physical disability or impairment; any other loss or abnormality of psychological, physiological or anatomical structure or function; and the presence in the body of organisms capable of causing illness.

(1) Where an applicant for employment or an employee is qualified for work of any description, it shall be unlawful for an employer, or any person acting or purporting to act on behalf of an employer,---

(a) To refuse or omit to employ the applicant on work of that description which is available; or

(b) To offer or afford the applicant or the employee less favourable terms of employment, conditions of work, superannuation or other fringe benefits, and opportunities for training, promotion, and transfer than are made available to applicants or employees of the same or substantially similar capabilities employed in the same or substantially similar circumstances on work of that description; or

(c) To terminate the employment of the employee, or subject the employee to any detriment, in circumstances in which the employment of other employees employed on work of that description would not be terminated, or in which other employees employed on work of that description would not be subjected to such detriment; or

(d) To retire the employee, or to require or cause the employee to retire or resign,---
by reason of any of the prohibited grounds of discrimination.

Were Section 22 to prohibit treating an employee or potential employee differently on the grounds of their genetic predisposition, Section 23 of the Act would appear to rule out requiring job applicants to undergo genetic testing.

It shall be unlawful for any person to use or circulate any form of application for employment or to make any inquiry of or about any applicant for employment which indicates, or could reasonably be understood as indicating, an intention to commit a breach of section 22 of this Act.

However, Section 29 of the Act allows employers to discriminate on the grounds of ‘risk of harm’ to the employee. This creates ambiguity in relation to genetic tests for increased risk of suffering harmful effects from exposure to workplace toxins.

(1) Nothing in section 22 of this Act shall prevent different treatment based on disability where---

(a) The position is such that the person could perform the duties of the position satisfactorily only with the aid of special services or facilities and it is not reasonable to expect the employer to provide those services or facilities; or

(b) The environment in which the duties of the position are to be performed or the nature of those duties, or of some of them, is such that the person could perform those duties only with a risk of harm to that person or to others, including the risk of infecting others with an illness, and it is not reasonable to take that risk.

(2) Nothing in subsection (1) (b) of this section shall apply if the employer could, without unreasonable disruption, take reasonable measures to reduce the risk to a normal level.

As an employers’ association representative noted:

[D]isability … is sort of loosely defined, and … there is an exception of a person [who is] … unable to do a job without risk to themselves or someone else because of the disability, then you can discriminate against [that] individual.

It would seem that much would depend on judicial interpretation of the word ‘reasonable’, and it suggests the possibility that potential employees could be screened for biomarkers of susceptibility, in the way that some employers currently put potential employees through physical stress tests to determine whether they are more likely to contract asthma from exposure to substances present in their desired workplace.
In those sorts of places where there are isocyanates around, it’s considered sort of very bad form for an employer not to check out whether an employee has got a tendency for asthma or not, and if they have they shouldn’t but put in an environment with any risk of that at all… The [aluminium] smelter people put people through specific challenge tests… If you have got any tendency to get bronchial spasm, you won’t be employed in certain parts of that factory. So yeah, the idea that if there were genetic markers which clearly showed that somebody was more likely to get something than the next person, then I think employers would be going down that track. [ACC occupational health specialist]

At this point the Human Rights Act intersects with the Health and Safety in Employment Act, which requires employers to take ‘all practicable steps’ to ensure health and safety of employees. The Act specifies the elimination of workplace hazards; or, if ‘all practicable steps’ do not result in elimination, the isolation of the hazard; or, if ‘all practicable steps’ do not result in isolation, monitoring the health of employees. It defines ‘all practicable steps’ as ‘all steps to achieve the result that it is reasonably practicable to take in the circumstances, having regard to’ not only what is known about the severity and likelihood of the potential harm and about the effectiveness of measures available to eliminate or reduce the harm, but also ‘the availability and cost of each of those means’. Again, much will hinge on the interpretation of the terms ‘reasonably practicable’.

The Health and Safety in Employment Act was seen by some of our interviewees as requiring that employers ‘keep the job safe as opposed to just take out people who might be harmed’. However, the current use of both self-reporting and medical tests to ascertain whether a potential employee has been exposed to or has reacted to certain chemicals, or has a propensity toward asthma, suggests that this is not a hard-and-fast rule. Administering genetic tests to potential or existing employees to determine their relative risk of harm from workplace toxins (setting aside for the moment the question of whether the tests are able to do this accurately and reliably) may even be seen to be required by the Act’s ‘all practicable steps’ provisions, which apply to ‘circumstances that the person knows or ought reasonably to know about’. If such genetic tests become more readily available, and are used in these ways in other jurisdictions, will they come to be seen as a ‘practicable step’ conveying information that ‘ought reasonably’ be known by employers?

The lack of New Zealand legislation dealing specifically with genetic testing in the employment context thus appears to create a number of dangers, two of which are:
Employers may find themselves caught between the requirement to take ‘all practicable steps’ to protect the health of employees, on the one hand, and the prohibition against discrimination on the basis of disability, on the other.

Employees or potential employees may find themselves required to take a genetic test as a precondition of employment or of undertaking particular tasks, perhaps as a result of an employer endeavouring to take ‘all practicable steps’.

The latter, of course, can be interpreted as a positive step in the direction of improved workplace health and safety. However, there are a number of features of genetic testing that suggest a need for caution. For example, many regard the information potentially derivable from genetic tests as particularly sensitive due to, e.g., the possibility it will provide unwelcome knowledge about one’s future (thus its ability to undermine what has been termed a person’s ‘right not to know’), social or psychological stigmatisation, its potential impact on access to insurance and employment, and its implications for family members. Genetic tests may also be treated by employers as more determinative and definitive than they are, thus unnecessarily costing people employment opportunities. Further, reliance on genetic testing may shift attention away from improvements that would make the workplace safer for everyone, toward individualizing the problem and the solution through the removal of ‘hypersusceptible’ workers.

Inclination and incentives to use genetic testing in relation to employment

Our informants noted past or present use of pre-employment medical questionnaires and examinations. Genetic testing was often seen another step on the same continuum:
It’s quite common for new employees or new job applicants to take a medical check. It’s only a question of how sophisticated that can be. [trade union representative]

An employment lawyer noted instances of an employer requiring that employees ‘should never have had a notifiable asthmatic condition’. According to our informants, employers were most likely to seek information about asthma, chemical sensitivity, back injury, and overuse injury. It was also pointed out that some employers currently administer psychological tests.

A representative of an employers’ association emphasised that employers currently rely heavily on self-reporting in relation to medical history:

You may be looking at things like, if someone is working or someone has had a sensitivity to a certain solvent or chemical and it wouldn’t be wise for them to go back into an environment with a possibility that they may be exposed to it, the same with some dusts and some asthmatics, and some chemicals might trigger a condition that you already have, so those things are generally looked at by looking at medical histories, which is often self-reported medical history. … The most common questionnaires would be about back injuries, overuse injuries and maybe exposure to chemicals, and it is the chemical exposure that is generally the most common area that is looked at.

The same informant noted, however, that employers are beginning to move away from reliance on self-reporting:

Now as employers get more sophisticated they ask for a doctor to do an assessment of an individual against the requirements of the job, but that would generally again be looking at physical characteristics [rather than a genetic profile].

Many informants spontaneously drew a parallel with workplace drug testing and the conflicts around it. It was seen by some as indicating some employers’ inclination to use the obligation to provide a safe workplace as a lever to increase their control over employees and invade their privacy inappropriately. They then emphasised the importance of considering employees’ privacy and dignity in relation to the use of genetic testing:

If what a person is doing in the workplace has no reasonable impact on the health and safety of co-workers or public or anybody like that, it’s very difficult to see why their right to privacy and dignity should be overridden in that kind of way [i.e, by requiring a urine sample for drug-testing]. So I guess if you apply the same analysis to the principles of genetic testing … and I haven’t worked through the philosophy of this, you’d come up with some interesting [questions, such as]…: ‘Is there a legitimate reason which would override an individual’s right to keep that sort of thing private?’ [employment lawyer]
Incentives

Few people saw the current process for setting ACC premiums as providing sufficient incentive for employers to use genetic testing to seek to reduce the incidence of workplace-related illness. However, the Partnership Programme would appear to provide much greater incentives to do so. The Partnership Programme allows the employer ‘to act as an agent of ACC, managing workplace injuries for your employees and providing entitlements under the Accident Insurance Act 1998 in relation to work-related personal injuries and illnesses’ (ACC 2001). The Programme essentially allows employers to fully or partially ensure themselves for workplace injury. The relationship between successful compensation claims and costs to the employer is much more direct than under the standard ACC scheme. This is the kind of situation in which, in other jurisdictions, employers have been interested in using genetic tests either to screen ‘susceptible’ workers or to gather evidence on the relationship between the workplace and the injury to be used in relation to claims for compensation.

Under the Partnership Programme, as acknowledged by an employers’ association representative, the incentives to consider using genetic testing are stronger:

A: They self-insure to a certain extent and they choose whether they do it for two years, four years, or for the life of the claim, so obviously if someone might have a long-term-effect kidney disorder then that could be a very expensive claim … if it was related to work that may require dialysis or kidney replacements or whatever.

Q: So there would seem to be a stronger motivation to [use genetic testing]?

A: [Yes,] when a person starts and possibly even when the person leaves. What’s their condition when they leave their employment so if a future injury occurs, and they could say, ‘well it must have been caused somewhere else and not by us.’

Q: Right, because when they left us there was no sign of it?

A: Yeah, either that or you previously caused it.

Both screening for relative susceptibility and screening for biomarkers of exposure and effect could potentially be utilised for these purposes.

Our interviews suggested that minimising costs of compensation for injury was not the only economic incentive employers would have to use genetic screening. Employees who become ill from workplace exposures can impact on the willingness of other employees to continue doing the job.

Q: [If]workers could opt into these tests,…, and they could make the decision for themselves, would you see it as feasible that this would happen and then
some of them would say ‘well it is still the best chance I have for a decent income so I am going to do it anyway’?

A: Well the downside of that, of course, is the employer then has to think, ‘well, can this person safely work in the environment?’, and they may know that they may be exposed or they may be harmed, and if I have done everything I can to limit their exposure as much as possible … if this person may be injured, whereas other people wouldn’t be, then you have got to kind of assure this other person here [that the job is safe for them].

There may also be incentives for employees to use genetic tests. Tests that look at relative susceptibility could be used to give employees and potential employees more information about the risks associated with the job. However, they are less likely (than employers) both to be able to afford such tests themselves or to act on the information, due to possibly limited income-earning options. Further, it is not clear whether they genuinely have the option of not disclosing the results to their potential employers (or insurers):

[T]here is probably more a move to say ‘look, these are the things you need to do, like lift 20 kg, twist, turn or stand all day, sitting up in a seat and do things and are there any medical conditions which would interfere with your ability to do that?’ And then you have to be careful what you write, and if you haven’t been honest that might affect your future employment. [employers’ association representative]

However, tests that look for biomarkers of exposure or effect, if positive, could potentially be used by employees to demonstrate the validity of their claims of workplace injury. This is discussed in section 3 below.

**Aspects of employment in which genetic testing may be most likely to be used**

**Job applicants**

It was noted by those associated with both unions and employers that job applicants would be those most likely to consent to genetic testing requested or required by employers. Here again a parallel was drawn with drug testing.

A: It would usually be easier to get a person’s consent when they are applying for a job … Drug testing is a good example of that because I guess that is sort of when you are looking at testing a blood sample or urine sample and it generally is much easier to implement in pre-employment than during employment.
Q: Right, just because people are much more likely to give you their consent?
A: That’s right, if you know that part of applying for the job is that requirement, generally you don’t apply for the job if you don’t want to do it. [employers’ association representative]

A union representative attributed this both to the limits of unions’ reach (‘We really only have an influence over what happens inside the workplace. It’s much more difficult to have an influence over what happens to job applicants.’) and to the imbalance of power occurring in a difficult job market. He illustrated this by describing a situation that developed when the national awards began to require that university-trained journalists would start at a higher pay level:

There was a time when jobs were short and employers were deliberately not employing university graduates because it cost them more … and we had a number of anguished approaches from university graduates saying, ‘can you not drop this thing,’ which was there for [their] benefit, ‘because it’s stopping us from getting jobs,’ and we had people who were concealing the fact that they had a university degree in order to get a job. … You know if people want something badly enough they will tend to do it, if they want something badly enough, they will avoid attempts to be helped.

In this sense, both susceptibility tests and tests for biomarkers of effect, if returning negative results, could be used by employees voluntarily in a competitive labour market to obtain an advantage. Were this to become common practice, failure to supply test results could be interpreted by employers as indicating a possibly ‘at-risk’ employee. Thus de facto genetic discrimination could occur even without a genetic test being taken.

**Exposure to toxic chemicals in the workplace**

It is worth noting that a number of our informants mentioned that workplace-related illness due to exposure to solvents and other toxic chemicals is expected to increase significantly over the next decades, as the results of earlier exposures to certain chemicals start to manifest themselves.

A: One very contentious one is this, you know, multiple chemical sensitivity or that type of condition, where you get a whole lot of symptoms but there is no real clear medical way of determining whether the symptoms are related to some sort of exposure, and if there was a test that could clarify that, then that probably would be welcomed. Because at the moment a subjective test is used in terms of what is your memory now like compared to [before] and do you have
dizzy spells and those sorts of things, because at the moment there is no sort of medical diagnosis for those sort of symptoms.

Q: Is there quite a bit of contention around the impacts and the effects of exposure to solvents?

A: Yeah, and that is probably something that is starting to have more and more effect now, because we are getting a legacy of people who have long-term exposure getting to the end of their working life and they may suddenly get a diagnosis of organ damage and loss of short term memory and all those sort of things. So, that is just starting to become more apparent now. [employers' association representative]

And, as noted above, employers are particularly interested in ascertaining a potential employee’s past exposure to toxic chemicals. Developing tests that detect biomarkers showing genetic susceptibility to or impacts of exposure to toxic chemicals is a major focus of toxicogenomic research. Some of the substances receiving attention by toxicogenomic researchers in the US and UK include dioxins, aromatic hydrocarbons, vinyl chloride, organophosphates in sheep dip and organic solvents in paint.1

**The importance of collaboration in any introduction of genetic testing in relation to the workplace**

A perhaps surprising variety of sources (occupational health specialist, employment lawyer, support-group member speaking as an employer) emphasised that the development of policies and standards for the use of genetic testing in relation to employment should be done through formal collaboration between employees (and their unions) and employers, with government as a possible third party in a tripartite process.

I think the same principals will apply which I think would apply to any aspect of work organization and occupational safety and health, which is, the only way to make any of those things, a., workable and, b., effective is to make sure that they are jointly owned and managed by workforce and employers … There’s two roles in all of this and there are two voices and there’s different lots of expertise. [occupational health specialist]

The only way it is ever going to work is if unions design it, if the workers themselves design it, get it all prepared and put it up and say ‘this is a done deal’, then there is no discussion needed; you either want it or you don’t, and if you want something like it, this is the only thing we are going to accept. You know, it has got to come from their side, and it has got to be so that they own it when they present it. It is all theirs and the employers have just got to swallow their pride, let alone want to take any credits for it. [former employer]
For one employment lawyer, the issue was not genetic testing itself, but the process for determining whether and how testing should be used in relation to employment: who would set the rules, who would set the standards for use?

New Zealand has not yet embraced tripartism. They still have bureaucratically led impositions of policies and standards, and there is no genuine tripartism. There is no mechanism in New Zealand for tripartite establishment of regulation. … What we have to have is something like an OSH Commission, which is a tripartite body that does the standard-setting, and … they would determine the actual standards and the mechanisms for the tests, and how they would be used. We don't have that, we need that. [employment lawyer] Further, the process of setting standards should be embedded in the New Zealand context.

I have always felt and so does the CTU that those standards should not be brought in from the bloody American hygienists or the Australians, that we should actually have a New Zealand standard-setting panel where we would have the Scandinavians, Americans, and other standards, and we would determine what was appropriate for New Zealand, but we don't. So standard-setting is really the critical part of it, and that would include [standards for the use of] genetic testing. [employment lawyer]

3. Accident Compensation Corporation

Genetic testing not currently considered by ACC

As in the employment arena, our interviews suggest that ACC is not yet considering the possibilities, challenges and dangers of genetic testing. The ACC occupational health specialists to whom we spoke were not aware of any current uses of or requirements for genetic testing by ACC. Nor does genetic testing figure in the recently published *Workplace Health and Safety Strategy for New Zealand to 2015* (Department of Labour 2005).

The specialists were of course aware of the technique of genetic testing, but the possibility of using genetic testing in the assessment of claimants, or the prevention of injury, was not something they had considered or that they were aware was being considered anywhere else in ACC. However, once the possibility was suggested, the specialists saw a potentially important role for genetic testing in relation to diagnosis and determination of causation, as well as injury prevention. There was considerable enthusiasm for this, with the specialists emphasising the difficulties they currently have in determining whether an injury or illness is caused by work environment or activity. This enthusiasm was hedged in various ways, however. One specialist emphasised that the tests must first be of
proven validity and utility, while another suggested that opposition from ‘unions and lawyers’ may prevent work-related uses of genetic testing.

**Possibilities for use in relation to ACC**

**Determination of causation of personal injury in the case of ‘work-related gradual process, disease and infection’**

A range of informants noted current difficulties in determining eligibility for ACC cover in the area of ‘personal injury caused by work-related gradual process, disease and infection’ (henceforth WRGPDI). The Injury Prevention, Rehabilitation, and Compensation Act 2001 sets out the criteria (the ‘three-part test’) according to which an injury qualifies under this provision: the person’s work activity or environment has a property or characteristic that causes or contributes to the cause of the personal injury, this property or characteristic is not found ‘to any material extent’ in the non-employment activities or environment of the person, and the risk of suffering the personal injury is ‘significantly greater’ for persons who perform the activity or are employed in that type of environment than for the general population. A particular sticking point noted by many of our informants is the final ‘epidemiological hurdle’, which requires there to be significant prior research and data collection and large enough populations involved to demonstrate statistical significance.

Exempt from the three-part test are the disease/occupation associations already recognised in Schedule Two of the Act. Most of these are derived from the International Labour Organisation’s List of Occupational Diseases as it was constituted at the time ACC was formed. The Schedule can be, and has been, added to as work-related injury causations are established to the satisfaction of the Minister for ACC. For example, ‘leptospirosis diagnosed as caused by working with animals or their carcasses’ has been added to the Schedule. Here, too, however, interpretation of the categories is not straightforward. Some items list specific diseases, e.g., ‘Lung cancer or mesothelioma diagnosed as caused by asbestos’, while in most cases it is the causative substance rather than the disease that is specified, e.g., ‘diseases of a type generally accepted by the medical profession as caused by benzene or its toxic homologues.’ While in the former cases, the phrase ‘diagnosed as caused by’ may provide leeway leading to disagreement, in the latter the phrase ‘generally accepted by the medical profession as caused by’ leaves even more room for maneuver and disagreement. As an ACC specialist noted, there is also uncertainty about what exactly is denoted by phrases such as ‘its toxic homologues.’

It was acknowledged by a range of diversely placed informants that WRGPDI is an area currently fraught with difficulty. Both union and employers’ representatives as well as ACC occupational health specialists noted the contentiousness and imprecision of, as
well as litigation around, decision-making in this area. If the stated goals of some toxicogenomics research programmes are met, it is possible that genetic testing could significantly impact upon WRGPDI decisions as well as the list contained in Schedule Two. As an ACC occupational health specialist noted:

A: How do we answer those difficult questions contained in the three-part test? We are often looking for things [to help us with that], and that might be where genetic testing might help us, with some of those questions… If there's something that's of use that helps illuminate the issues we've been talking about, then we'd welcome it.

This specialist had in mind the importance of getting the diagnosis right so that people are not needlessly kept away from work while the actual cause of the problem remains unaddressed. But it is clear from the American ‘toxic tort’ literature that genotoxicological testing may be particularly likely to be used in the context of disputed claims, especially when they reach the courtroom. Biomarkers of exposure or effect could be argued to be definitive proof of a particular work-related disease causation, while lack of such biomarkers could be argued to be proof of lack of such causation. Biomarkers of heightened susceptibility could be argued to increase significantly or decisively the weight of evidence in favour of work-related causation, while lack of such biomarkers could be used to argue that a claim should be rejected as the likelihood of such causation is too low. Whether such arguments have merit is another question – a question that may end up being answered by judges attempting to adjudicate claims and counter-claims by interpreting the science of genetic testing.

Many of our informants were convinced that the so-called ‘eggshell skull principle’ would prevent the use of genetic tests demonstrating heightened susceptibility to disqualify someone from cover on the grounds that the problem could be classified as an underlying medical condition. The eggshell skull principle is a generally accepted interpretation in workers’ compensation insurance that claimants must be taken ‘as they are’ – it stems from a case in which someone with an unusually thin skull suffers more serious injury from a workplace accident than would have otherwise occurred had the skull been of normal thickness. The full extent of the injuries would be covered, as, while the underlying condition exacerbated the injuries, the injuries would not have occurred at all without the accident.

However, the ACC specialists pointed out that, while many assumed the general applicability of the eggshell skull principle in relation to ACC claims, in the area of work-related disease (as opposed to accidents) the weight of legal opinion rejects this. According to this specialist, it has ‘largely’ been decided that, in the case of WRGPDI,
the eggshell skull principle is superceded by the three-part test. Thus, even if it can be demonstrated through the presence of biomarkers of effect that exposure to a workplace toxin caused a particularly susceptible employee’s illness, the illness must still overcome the test’s epidemiological hurdle (that is, the illness must be accepted as significantly more likely to occur in association with that work environment or activity than among the general population) in order to be covered by ACC.

**Injury prevention**

A range of informants reacted positively to the possibility of using genetic screening as a tool to lower the incidence of work-related disease. An ACC occupational health specialist welcomed the idea and thought it might well come to be seen as an employers’ responsibility, along the lines of current tests assessing susceptibility to asthma. While noting that this also fell under the purview of OSH and the Department of Labour, this informant noted that ACC also had an interest in this area: ‘If there’s something which would stop claims happening or stop people getting diseases we would want to be promoting [it].’ While an employers’ association representative emphasised that ‘the overriding obligation of the employer [under the Health and Safety in Employment Act] would be to try and keep the job safe as opposed to just take out people who might be harmed, … so the testing would be the last resort as opposed to the first,’ the specialist saw employers as likely to embrace the technology: ‘if there were genetic markers which clearly showed that somebody was more likely to get something than the next person, then I think employers would be going down that track’. Both ACC and employers’ association representatives saw the Partnership Programme as providing an added incentive for employers to use genetic screening in this way.

Genetic testing was also seen as an appropriate tool to use in the rehabilitation process, in terms of assessing where an individual might safely resume work. As another ACC occupational health specialist noted: ‘I think it would be a tremendous advantage if you are putting people into that job and you had an easily done test that tells them “hey, you shouldn’t do this because your chances of getting this condition are increased a hundred-fold, you should be doing something else.”’

The notion of using genetic testing to determine one’s susceptibility to harm from workplace substances or processes also appealed to support-group members, but that appeal was complicated by their concerns over who would have access to the information and how it would be used. If screening could come to be seen as an employer’s responsibility, could acting ‘responsibly’ in the light of genetic information come to be seen as a potential claimant’s responsibility?
This relates to what several people referred to as a “grey area” in ACC practice: if a person knows that he or she has a statistically higher risk of contracting a disease from a workplace, but works there anyway and develops the disease, is that person covered by ACC? Some thought that the eggshell skull principle would apply, and thus the person would be entitled to cover (though support-group members thought the person would be made to fight for it). But if, as noted above, the eggshell skull principle does not apply to work-related disease (or to WRGPD1 more generally), and the claim passed the three-part test, what would be the impact of ACC knowing that the individual knew that he or she had a greater risk of contracting the disease in that environment (and thus perhaps could be said to have gone against medical advice)?

A further issue relates to whether genetic screening is the approach one would use if one started with the problem of work-related injury rather than with the putative solution of genetic testing technology. Are there other more effective or less potentially harmful ways one could reduce the incidence of workplace disease? A number of informants suggested that there is still much that is not being done – for example, keeping better records on workplace exposure to toxins and setting fines for health and safety violations that would provide sufficient incentive to improve the workplace:

That’s the real risk with the process of genetic screening; it will have nothing to do with the health and safety or the rights of the working people. … We don’t even know what’s being used in workplaces in New Zealand. There’s no official record of who’s been exposed to what. … I know for a fact that at some particular enterprises, it’s quite a clear calculation as to what you [pay] in OSH fines, compared to what it would cost to deal with the hazard. [occupational health specialist]

Aspects of ACC practice that could influence the social implications of genetic testing in New Zealand

Access to and handling of personal information

An individual’s genetic information may not only be regarded by that individual as highly personal and private; it may also have implications for an individual’s access to employment, health care, and insurance, as well as for their psychological well-being. In addition, the nature of genetic information is such that it is likely also to be consequential for family members. As a result, discussions elsewhere have emphasised the importance both of safeguarding genetic information from unauthorised access and of protecting people’s ‘right not to know’ their genetic profile (see, e.g., UK Human Genetics Commission 2002; McNally et al 2004).
None of the support-group members with whom we spoke had confidence in ACC’s ability to safeguard genetic information. This lack of confidence was the result of their experiences with ACC. These experiences included ACC claimants being sent other people’s records, as well as confidential information being accessed by inappropriate people within ACC.

I had a person ring me about three or four weeks ago who had requested a copy of their file and got a copy of someone else’s completely different file. It wasn’t their file at all. It was the other person’s, and she actually rang the person and said I have got a copy of your file, and that person was going to go to their MP because it was a breach of privacy, a total breach of privacy.

Q: [What is your view of] the ability of ACC to keep confidential records confidential?
A: Don’t even go there, oh dear, oh dear. … We had several members in our group where one man had had five different people’s information on his file.
A: Was it mailed it to him?
F: Yeah … [P]eople are requesting full copies of their files, and so these full copies of files are being mailed to the claimant, and in amongst it will be information on other people. It may be as small as just someone else’s name, which in itself is a breach because it identifies them as a claimant, but the worst examples we had were a woman’s medical information, which included a letter from her GP and also a letter from ACC to the woman, and it was very personal, and basically the guy who got it – her address and everything was on it, so he actually rang her up and she came and picked it up. … That’s probably the worst example because it deals with sensitive personal information but we had another example where a person’s bank account number and all their information was also included.

I mean you would get people [at ACC] that knew too much about you, that had looked into not my [standard] file but my ‘private’ file, and they shouldn’t have been able to look at my sensitive issue claim because it was – appropriately – held in Wellington, and no one [at the local branch] could see it, but this person knew absolutely every detail about my sensitive claim that they shouldn’t have.

One of them got information about me that they had no right [to] or were [not] entitled to, and they subsequent released information from my file that they had no authorisation to release as well, and I complained bitterly, and I actually got a written apology out of them for doing it.
The [local ACC] branch actually admitted that they have – what did they say, not mature – “senior” school pupils doing photocopying. Now, I am sorry, but you cannot convince me that a 16, 17, 18 year old even begins to understand the ramifications of stuff like that getting into the wrong hands.

It is important to note that these incidents are not derivable from the formal procedures or legal constitution of ACC, or from other legislation, such as the Privacy Act. They are aspects of everyday practice; it is this everyday practice within which genetic testing would be situated and which therefore would shape the actual social impacts of genetic testing.

However, there are also areas – possibly “grey” areas – of formal procedure that come into play. Concerns about the inappropriate handling of personal information were exacerbated by ACC’s current ability to access a wide range of personal information, particularly, but not exclusively, medical information. While some noted that doctors can and should consult with patients about what information could be justifiably released to ACC, others emphasised that in practice ACC use the consent supplied on the initial ACC claim form to obtain wide-ranging information.

They are getting you to sign a blanket consent. I mean when you go onto ACC you sign a blanket consent for the release of all information. Whether you know that or not is dependent on whether you have read the very fine print at the bottom of the first page, which a lot of people don’t. And they don’t realise that when they sign their name, because they have to sign it to get a claim, that they are actually signing away their whole life’s knowledge basically. [support-group member]

What people get caught by is the blanket consent form … And once you give blanket consent they can go to anyone, anywhere, anytime and ask anything, and if they deem it to be relevant, then they are entitled to ask for it. What more and more claimants are doing now is limiting that consent and saying you tell me who you want to go to, what you want to ask, and I will give you consent for that, and ACC are not happy with that at all. … If you haven’t got a lawyer they tell you that you are non-compliant, and until such time as you sign that consent form they are not going to [consider your claim]. … So yes privacy is a big issue and I mean there have been, for example, say, women who have been sexually abused, and that may have absolutely nothing to do with the fact that they then developed OOS, but the problem is of course that if ACC gain access to all the prior medical information and history then they could pick up on that and say ‘well obviously you know the fact that you were abused meant that you were more
susceptible to … and therefore you are not covered’, you know? And that is an issue, and we have had people whose medical records have been accessed when they shouldn’t have been, because they weren’t relevant. [support-group member]

A: ACC have gone to e-lodgement with their forms and on the bottom of those forms it actually says that you agree to ACC collecting any information about me. Now, that’s a huge change.

Q: That could be your tax information? It could be anything?

A: Yeah, it could be anything, and you see if they have a blanket consent form they can go anywhere. [support-group member]

The current move to holding medical information on centralised electronic databases, which raises more general issues around privacy, also raises issues regarding inappropriate access by ACC to medical records, as well as confidentiality of ACC-related records filed electronically. An informant who had worked with electronic databases in an unrelated medical research project pointed to potential impacts on people’s privacy as well as on their relationship with ACC.

Anything that is entered on a computer is accessible, unfortunately, and I think, you know, people are naïve to think otherwise. … [T]his is one of the issues that has come up recently with ACC …. Once [the electronic medical records system] is all linked up, and it will be linked up, then basically if my medical records are on my GP’s computer, [ACC can just] type in my National Number or whatever it is called, you know the number I mean, and up pop all my records without my consent [and] without my GP being able to filter it. [support-group member]

In the U.S., where health care is dominated by private insurers, there are well-founded concerns that people who might benefit from genetic testing (e.g., those for whom knowledge of a higher genetic risk of a particular cancer could lead to closer monitoring or prophylactic treatment) will avoid it in order not to be denied health insurance. A similar situation could arise here in relation to private health insurance; but the above discussion indicates there is also a potential for it to arise out of concerns about ACC access and decision-making.

Further, with employers acting as the insurer within the Partnership Programme, the issue also arises as to how adequately employers could or would handle genetic information. The following description by an employers’ association representative suggests that the current situation is not sufficiently protective of employees’ privacy.

A: That is always the worry that occurs when testing a blood sample – what else it is going to be used for? And normally the consent form would have quite a lot of detail of what the test is for, again this is a privacy requirement now as to who
Q: Okay, and what is generally the agreement in terms of where the information ends up? I mean after it has served its function does it get destroyed?
A: Generally it should be, yeah. I mean if you are going to keep it you would have to have good reason to keep it, and it comes under several bits of legislation including Privacy and the Disability Code I think it is, and sort of dictates how you keep it secure, and again you have to make it quite clear, define who has access to it and for what purpose. So, it is a reasonably regulated area as long as people stick to their obligations. [emphasis added]

It was suggested that an appropriate approach to the use of genetic testing might be for the employer (in a workplace that carried risk of occupation disease) to cover the cost of the testing; employees and potential employees could decide whether to undergo the testing, and the results of the testing would remain confidential to the individual employee. However, an employers’ association representative suggested that this was likely to encounter resistance from employers: ‘If you are doing a test and can’t get any access to any information or you can’t use that information, I guess you would think why am I doing this test or why am I paying for it.’

Ability to require that claimants undergo medical diagnostic and evaluative procedures

Given the potential sensitivity of genetic information, should ACC be able to request that claimants undergo genetic testing for diagnostic or rehabilitative purposes? Currently, ACC can request claimants to undergo whatever diagnostic procedures it considers necessary in order to evaluate the claim. The ACC occupational health specialists did not expect genetic tests to be treated differently in this regard: ‘Certainly there’s an obligation to explore most things and I don’t think any form of testing would be contraindicated whether it be genetic or any other.’ (However, one ACC health specialist saw the use of genetic tests in relation to employment as likely to be challenged in the courts). Claimants cannot be compelled to undergo the procedure, but should the claimant refuse, it may significantly decrease the chance of having their claim accepted: ‘the quality of the evidence that’s considered is less and that will normally mean that there’s less likelihood of getting it accepted than if the quality of it were there.’ A support-group member had a somewhat more jaundiced view of this process, and also noted how this practice bears upon the social implications of genetic testing and how genetic testing may exacerbate the potentially negative impacts of the practice:
If they want to send me for an evaluation, a medical assessment, I have to go. If I don’t go, they say I am non-compliant and therefore they cut you anyway, so I believe that the genetic testing would be seen in the same way. It would be an interesting Human Rights issue, actually, because the implications are much wider of course in terms of gaining employment and even health insurance and those sorts of things.

Employers who are self-insuring under the Partnership Programme have the same ability as ACC to ‘require’ tests in this sense.

**Corporate structure and culture**

Among the ACC claimants to whom we spoke, there was a strong and widespread view that aspects of ACC’s corporate structure and culture undermined its substantive goals. Case managers were seen as both overworked and encouraged through the pay structure to focus primarily on reducing payouts to claimants; claimants were seen as dependent upon the good will of the particular case manager.

It is the fact that the incentives are distributed right down to the coalface … They’ve got the financial incentive to deny rather than, as the law says, to meet their obligations and, once cover is accepted, to make sure the entitlements are delivered.

Case managers carry horrendous loads, and they of course have KPIs, Key Performance Indicators, which you know are good things to make sure you are doing your job, but with some of their KPIs it is easy to meet the criteria without actually doing a good job. So you know I think it should be about real rehabilitation and getting people back into real jobs rather than saying you are fit for work and you have got three months and off you go. And if you don’t find anything, well, that’s your problem, you know, we will show you how to join up at WINZ.

A lot depends on who your case manager is. .. I would say that I have had probably two who have expressed to me that they would have liked to have been able to help me more than their brief allows them to, yeah. One in particular, he had bent over backwards to try and help me get back to work … And from my understanding he still is doing everything he can to help the few people he has got under his care, but others just love the fact that they are not allowed to give you anything, and they throw the rulebook at you and say ‘we cannot do it, because the rulebook says we cannot give you Home Help or we cannot give you this.’ And they just, yeah, love the fact that they can do that. So, it definitely does depend on your case manager and to a degree the branch as well.
Overall ACC is seen by those in occupational-injury and ACC-claimant support groups as putting financial considerations ahead of claimant well-being. Support-group members emphasised that there was a ‘gap’ between formal rules and actual practice, that ACC were ‘a law unto themselves’, and that legitimate claimants often had to fight to get the cover to which they were entitled. There was tremendous distrust of ACC and great concern that genetic testing would become another tool in its arsenal to deny legitimate claimants the compensation they are entitled to.

So, what I see the problem with some of this testing is that, whilst new claims could be denied right from the outset, it would be a means of also removing people from the ‘tail’ [of long-term claimants] which is what they are trying to get rid of, and if we suddenly had to undergo genetic testing in order to identify whether we had been predisposed, even though cover had been granted, [and] they could then deny it.

The biggest issue at the moment seems to be getting down the number of people, and they are doing that in whatever way they can, and that would be one of the ways I think of using it, to say ‘well you can’t possibly have chemical sensitivity because you know it is not showing up on [genetic tests for susceptibility], so therefore it must be something else; this is probably in your mind or whatever’. Like, you know, you are depressed.

It used to be very common in this country [that] if you [were] liable to pay out because of your negligence, if the other party was in fact partly negligent for his own misfortunes then … he doesn’t get as much money. He is less at fault than you are but he contributed to his own misfortune. And in a no-fault system that is not supposed to be an issue. You can’t have it, but it exists [in ACC nonetheless], and this is where the business of genetic testing does get wrapped in; it stumble

I think that if there were genetic tests available that identified things like depression or predisposition to chemical sensitivities and those sorts of things, ACC would be using them very freely to identify people who may not be able to then gain cover … My understanding is that ACC don’t like the eggshell skull principle and I believe that this would be another way of declining cover. Whilst, you know, we should be taken on how we are and just because I have got a predisposition to something shouldn’t mean that I am excluded but probably will be.

It is worth noting that the an ACC occupational health specialist expressed personal unease with the idea of using genetic testing in this way:
A: It's a little bit about going back to that eggshell skull thing, that I think we've got to take people as we find them; no it doesn't appeal to me to be trying to do that sort of thing [i.e., looking for predisposition to depression as an alternative explanation for symptoms]. I think you could screen where your screening test was good … and … had a very specific consequence which you could spell out in terms of harm to the individual. I don't know that we would be looking at it from the viewpoint of saying, 'well, we're going to say this is not caused by work because you've got a genetic predisposition to it anyway, so we're going to say it was more likely caused by non-work.'

Q: You don't see that happening?

A: I don't, no I don't.

The expectation on the part of the support-group members was based partly on their experiences of ACC 'fishing' for a medical opinion that allowed them to deny a claim. As one support-group member put it:

In the nineteen reports [from doctors] they sent me to, every one of them was in my favour, but they just kept fishing and fishing and fishing, trying to get one that was against me. And they did eventually get one that was against me, and it was a guy that wrote a report on [the basis of] my file; he never actually saw me or spoke to me, and it was on [the basis of] that one report that they cut me off.

What these comments suggest is that the implications of genetic testing hinge critically on wider areas of ACC practice, both authorised and unauthorised.

4. Genetic testing in the workplace and ACC: the power context

The interviews provided support for the idea that any assessment of genetic testing and its implications must focus on the particular contexts in which that testing might be used, rather than simply attributes of the technology or general bioethical principles. What emerged particularly strongly from the interviews is the importance of the power relations characterising the particular context into which the technology may be inserted.

From support-group members, we heard the message repeatedly that the sizeable resources of the corporation were used to discourage claimants from pursuing what they believe to be legitimate claims, and that genetic testing had to be seen from this perspective.
There are more and more people now saying I can’t be bothered fighting it any longer, I have got to give up, I have got to find a way to get on with my life and put up with the pain or do whatever, because they can’t carry on fighting, they haven’t got the financial resources and they haven’t got the physical energy to carry on fighting.

I can’t keep fighting a corporation that has got endless amounts of money to say that I am not disabled. Yeah, it is a huge problem and if they had genetic testing it is going to make it worse. It is just going to open a can of worms. I mean it is going to make it almost impossible for people to fight. … if they get a reading back saying okay you are predisposed to OOS, that’s it, there won’t be any arguments, people won’t be able to fight it.

I think the problem is that when you are dealing with ACC and you are one person you will simply be declined cover. … They will just deny or decline, then in order to actually get cover will involve a protracted review, a legal, expensive situation and most people don’t bother, you know, so I think denial right from the word go is going to be the issue.

People with disabilities are some of the most marginalised people, and I think you come up against a machine like ACC and it is very daunting, and people do walk away, and that’s what they count on. And it is the insurance principle, you know, you deny ten people and only one is going to fight back.

You know, you are up against a machine that has huge amounts of money, which is taxpayers money, and they have all this money at their disposal and you have little individual people like the couple on there saying “well you know $67 a week [compensation], when it was workplace-related and, okay, because it was asbestos rather than he had his leg chopped off, you are denying it” and that saddens me incredibly. I just think you don’t do that to people, you know, but it is very insurance-like.

The financial relationship between ACC and the government was seen as creating a situation in which the government, no matter which party is in power, has little interest in shifting ACC away from this ‘insurance-like’ orientation toward its claimants.

We are supposed to have an Occupational Diseases Register but all Governments have steadfastly avoided eliminating the distinction between environmental poisoning and poisoning in the workplace. … [The big chemical companies] know that damage has occurred and not only do they hide it, but it would seem in the Government’s interests, notwithstanding they are supposed to represent us and we voted for them, it is in the Government’s interests to play along with
that. So, therefore you have this crazy situation like you do in New Zealand where these chemical companies are allowed to do what they would be sued for in America big time. … They know that the evidence is in and that those companies are aware of the risks to the individual workers, but for some reason people who work for them and the ordinary citizen is of no concern, and it is a question of putting their product out there. … The willingness of Government to do anything about it is not there. It doesn’t matter which Government it is and which party it is, they are not interested. They are not interested in allowing ACC to be exposed to any more liability. [support-group member]

In this view, Government’s interest in protecting the financial position of ACC provides an incentive not to recognise disease as work-related and thus ultimately weakens the drive to reduce the incidence of work-related disease. If a disease (or disease cluster) were recognised as work-related (e.g., through placing it on Schedule Two), it could significantly increase total ACC payouts. Of course, the cost of treating the disease in any case would fall primarily on the public health system, and the costs of support of the injured employees would simply be redistributed within the public sector (through payment of an unemployment or disability benefit), but the level of total support paid out is likely to be significantly lower.

This relationship between Government and ACC would heighten the imbalance of power facing claimants.

I honestly don’t see how they can continue at a Government level to actually deny that these things are happening, but you know you are fighting against something that is incredibly powerful and you can almost see them close ranks. [support-group member]

This is seen to impact negatively upon the ability to implement genetic testing in a way that would protect the rights of employees:

Q: So, what you are saying is that the tests should be made available and the results should come back simply to the worker or the potential worker, and it is up to them to decide whether they want to take the risk?

A: That is really where, you know, if you are going to have a truly democratic arrangement, then that’s where you have got to take it. You have to be able to put it to the worker. Of course, what the Government is going to say in a no-fault insurance system is that ‘we are not going to allow that worker in there because he is going to become a risk to us.’ [support-group member]

The relationship between government and employers also shapes the power context into which genetic testing would be introduced, as, of course, does that between
employers and existing or potential employees. An ACC occupational health specialist, reflecting that the three-part test actually constituted ‘quite a high hurdle’, alluded to the significance of the former:

[The current three-part test] really reflects a reluctance on the behalf of Parliament to easily ascribe things to being caused by work…There’s always been a sense that for whatever reason, and it might be that employers are quite influential people and they manage to, they’re very keen that things don’t unnecessarily get ascribed to them unless there’s good evidence.

In relation to the question of whether employers fulfil their obligation to make the workplace as safe as possible, another occupational health specialist pointed to the power differential between employers and employees:

[In] another industry, which will remain nameless, … because [the workforce] are unskilled people in areas where there’s not a lot of employment, if you injure a few, well ACC picks that up and there’s always someone to take their place. And that’s also a very big influence on people in the workplace because you know if you don’t do what you are told, somebody else will get the job.

Again, this highlights the importance of going beyond statutory requirement to actual practice when assessing potential impacts of a technology such as genetic testing.

It was also suggested that there is a danger that the focus on science-based, individualised technical tools will exacerbate the imbalance of power by diverting attention from significant contextual factors. An occupational health specialist noted that health challenges tend to accumulate and compound among those in lower socio-economic deciles; genetic testing may shift the preventive health focus away from addressing this context of relative vulnerability towards a more reductionist, individualising and ‘compartmentalising’ approach.

In fact, what makes a person cope or not cope in a particular work pattern is probably more related to their socially important network situations [and] their family situations than it is to biology or even to the specifics of the rosters that they’re working, and you can’t look at only the workplace functioning and get a view of whether a person is going to stay well and safe long-term in a particular job. … We tend to get into a simplistic mindset about genetics determining a great deal more than it actually does in terms of workplace or any other functioning. … We often get ahead of the science in our area and scientists are responsible [for it], they oversell. And they oversell on the basis of the truth from the laboratory studies which worries me. … I think that we’re compartmentalising people and we’re devaluing certain aspects of them, and
that to me is very worrying… I would rather have more of a community focus, a whole person in their role in their family and in their community, and work is part of that … So there’s a whole lot of much bigger questions other than the genetics but I fear that we’re going to run that way because that makes the science sexy. .. Of course it does look like the magic bullet, and everybody is out there looking for the magic bullet.

But could genetic testing, in fact, work in favour of the less powerful, rather than against them? A lawyer acting on behalf of ACC and other personal injury claimants saw the possibility of using tests for biomarkers of exposure and effect in a very positive light, as a way to demonstrate scientifically that which has been denied on the basis of epidemiological evidence. In particular, this informant saw the potential for its use in connection with the incidence of birth defects among the children of military servicemen exposed to Agent Orange and to radiation from nuclear weapons testing. While this would relate to a direct claim for Government compensation rather than for ACC coverage, the same possibility for use appears to apply to illness among workers and children of workers exposed to toxins in the workplace. However, as we’ve seen, such claims would still be expected to surmount the epidemiological hurdle in the three-part test for eligibility. The test result in itself would not be sufficient. (It is also not clear whether anyone who had not actually been present in the relevant workplace – i.e., the affected child – would be able to make a claim for compensation from ACC.) In relation to another obvious possibility, that of testing being provided to employees to make their own decisions (with the information remaining confidential to them), the preceding discussion has indicated that distribution of power within the employment relations context is likely to influence both the prospects of this happening and its implications for the most vulnerable workers.

5. Conclusions

In New Zealand, regulatory responses to the social challenges represented by genetic testing have been minimal. We found no evidence that the particular challenges represented by genetic testing for the areas of employment and insurance for work-related injury have been recognised or that a policy response is being developed. This report suggests that there is good reason to doubt the apparently widespread assumption that New Zealand’s Privacy, Human Rights, and Health and Safety legislation offer sufficient protection. In 2004, the Human Rights Commission acknowledged that in the areas of employment and insurance, ‘[t]here is potential for discrimination on the basis of genetic testing and our current laws may not be adequate to protect against this’ (Human Rights Commission 2004).
Recent work carried out by or on behalf of the National Advisory Committee on Health and Disability (Sarfati 2002; While and McLeod 2003; National Advisory Committee on Health and Disability 2003) has focused primarily upon the bioethical principle of informed consent as well as on knowledge of and attitudes toward genetic testing among general practitioners and on how to ensure technical quality in the genetic testing process. The more broadly social and more particularly embedded issues such as those discussed in this report have been neglected.

A number of our informants queried the reliability of genetic tests, with good reason. Genetic tests are being marketed before their analytical validity, clinical validity and clinical utility have been established (Marris 2005; McNally et al. 2004). According to the OECD, ‘discussions concerning criteria to establish the validity and utility of genetic testing are at an early stage in many OECD countries’ (OECD 2005); New Zealand would appear to be one of them. As the establishment of validity and utility is not simply a technical exercise, it would be inadvisable simply to adopt standards developed elsewhere:

There is no accepted methodology for establishing the clinical utility of a genetic test. Although the technical evaluation of test properties might be a scientific matter, the standards for test use are influenced by societal values. Many competing interests are at stake, including the value that consumers and health-care providers place on genetic risk information, the relative weight that is attached to preventive and primary care within a health-care system, the costs of genetic services relative to other healthcare services, and the commercial interests of test developers. (Burke and Zimmern 2004)

This recalls the words of the employment lawyer, noted above, to the effect that New Zealand needs its own standard-setting body that would consider what is appropriate in the New Zealand context, rather than simply importing American or Australian standards. One can therefore expect the marketing of tests with levels of analytical validity and clinical validity that, should the tests be used as an injury prevention tool, would result in situations in which many who would not be harmed are excluded from particular jobs or types of work, while others who will be harmed are neither identified nor protected.

Unless a genetic screening program employs a test with very high analytic and clinical validity, significant numbers of false negative and false positive results can be expected. Results that incorrectly label workers as having increased susceptibility or provide false reassurance that they are not at increased risk undermine the ability of the screening test to provide a health benefit and increase the likelihood of ethical, legal and social costs associated with genetic screening.
programs. For this reason, any plan to use genetic susceptibility screening programs to reduce occupational illness and injury must include a careful assessment of the analytic and clinical validity of the genetic test to be employed, as well as an assessment of the measures to be used to protect susceptible workers. … [I]f testing is contemplated as a means to protect workers, the threshold for test use needs to be debated. At what level of clinical validity is the test acceptable? Specifically, what proportion of false positive and false negative test results is acceptable in a workplace genetic testing program? (Battuello et al. 2003, 35, 39; see also European Group on the Ethics of Science and New Technologies 2003)

These, like the other issues raised in this report, are not technical questions. They deserve wide societal debate.

6. References


**Footnotes**

1 See www.niehs.nih.gov/envgenom/home.htm and www.ukems.org/groups/igg.

2 Analytical validity is the accuracy with which a test can identify the particular DNA sequence, or genetic mutation, being targeted. It is a question both of the quality of the test and the competence of the laboratory. Clinical validity refers to the test’s ability to detect or predict a particular disease (detecting the presence of a particular genetic mutation may not be sufficient to do this). Clinical utility refers to the actual health benefit offered by the test.