Part Six DISCLOSURE, CONFIDENTIALITY AND PRIVACY ISSUES

1 INTRODUCTION

This section focuses on how minors may discover that they are at increased risk for a heritable genetic mutation, or that they have been tested for risk status (where this is the case). We also explore the privacy implications for minors who have undergone genetic testing on the basis of parental consent, and minors who may be considering genetic testing on the basis of their own informed consent. The privacy implications involved in the information arising from genetic testing are huge, not least because of the familial nature of the information. The focus of this report is on whether genetic testing raises new privacy issues for minors in particular. The broader issues of family entitlements and obligations, and professional discretions and duties in relation to familial genetic information, cannot be canvassed or resolved to any great extent in this report.

2 DISCLOSURE OF FAMILIAL GENETIC RISK TO A MINOR

> *Well I suppose basically it depends on your make up and what sort of person you are, but I, perhaps I'm over protective, and I feel that why give them something to worry about which might or might not affect them? I had it in the back of my mind nearly all my married life and if it wasn't necessary, you know, as long as they needn't know about it, it was the amount of time that I could protect them if you like. Whether or not the ethics of them having the right to know, I didn't think about that … I would be hurting them by telling them …*[1]

> *… she was afraid to give children and teen-agers information that might lead them to believe that 'they were sick, that their breasts were somehow or other going to kill them.'*[2]

This first section examines disclosure of familial genetic *risk* specifically, and not disclosure of a minor's genetic test *results*, which are discussed separately later. Usually, in order for a competent minor or an adult to seek genetic testing, she must be aware that a heritable condition exists in her family and that she is at risk. It would also be useful to know that genetic testing for the condition was possible. This knowledge may come from her parents, from wider family or whānau, from persons outside the family, or from her own observations and concerns or deductions.

Should, and if so, when, how, what and by whom should minors be informed of their genetic risk status?[3] These are difficult issues, and much of the relevant discourse will lie outside the mandate of legislators, regulators and policy-makers.

2.1 Disclosure from a health professional

Due to confidentiality obligations and privacy regulations health professionals generally cannot inform a minor that there is a heritable genetic condition in the family for which the minor may be at risk, if by revealing the information the health professional will breach another person's privacy.[4] The familial nature of genetic information means that if a minor is informed of genetic risk status, without being symptomatic or having been tested, then the minor will become aware that someone else in her family is similarly at risk or affected. This type of disclosure usually cannot be made without the permission of the person from whom the health information came (e.g. perhaps a parent with an identified inherited genetic mutation).

There is an issue of whose health information heritable genetic information is. Is genetic information the health information of the individual from whom it was gleaned, or is it the family's health information? If genetic information is considered to be the family's health information then arguably privacy and confidentiality would not be breached by the health professional discussing the genetic information with any of the family members. This conceptual issue is not uniquely related to the relationship between minor children, their parents and health professionals: its resolution may have much broader application and so it cannot be covered effectively in this report which focuses on genetic testing of minors.

2.1.1 Exceptions permitting disclosure

There are exceptions to the general prohibition on disclosure: personal information about an identifiable individual *may* be disclosed if the health agency believes on reasonable grounds that it is impracticable or undesirable to obtain the person's consent *and*:

- the information is disclosed to a person nominated by the individual concerned or to the principal caregiver or a near relative of the individual concerned in accordance with recognised professional practice and the disclosure is not contrary to the express request of the individual or his or her representative (rule 11(2)(b), HIPC 1994);
- the disclosure is made to prevent or lessen a serious and imminent threat to public health or safety or the life or health of the individual concerned, or another individual (rule 11(2)(d), HIPC 1994).[5]

Note that in circumstances such as these the health agency holding the information has the *discretion* to disclose the information, and not a duty. Dawson comments that 'This discretion should be exercised on a principled basis, following the established policies of that agency or the ethics of the relevant profession.'[6]

The person's consent to disclosure should usually still be sought by a health agency seeking to disclose information pursuant to one of these exceptions in rule 11(4): disclosure can only be made on one of these grounds when consent to disclosure is 'not desirable or not practicable'.

Disclosure under any of the exceptions above is also permitted only to the extent necessary for the particular purpose (rule 11(3), HIPC 1994).

> *This limits both the scope of the material that may be disclosed and the range of people to whom it may be sent. Only the minimum information necessary to advance the authorised aim should be disclosed, and it should be passed only to those with a proper interest in receiving it or with authority to take the necessary action.*[7]

2.1.2 Disclosure to a person nominated or principal caregiver or near relative in accordance with recognised professional practice and not contrary to express request

This exception seems primarily directed at allowing health professionals to disclose certain health information about a patient to someone who is involved in caring for the person and may have to make decisions for that individual (whether medical decisions or otherwise). A 'principal caregiver' for the purposes of the HIPC, 'in relation to any individual, means the friend of the individual or the member of the individual's family group or whānau who is most evidently and directly concerned with the oversight of the individual's care and welfare.' Thus the 'principal caregiver' or 'person nominated' will generally not be a minor child. Despite the exception permitting disclosure to 'a near relative,' the provision was not intended to cover disclosure of a competent person's genetic information to a near relative, without that person's knowledge or consent. Such would not be a disclosure in accordance with recognized professional practice. Additionally the consent of the person whose health information might be disclosed would need to be sought before disclosure: generally pursuant to rule 11 of the HIPC, and also pursuant to the requirement that disclosure not be against their express request.

2.1.3 Disclosure made to prevent or lessen a serious and imminent threat to public health or safety or life or health of individual concerned, or another individual

In order to disclose under this exception, an agency needs to believe on reasonable grounds that:

- there is a serious threat to public health, public safety or the life or health of an individual;
- the threat is imminent;

- the disclosure of the information would prevent or lessen that threat; and
- the disclosure of information is necessary to prevent or lessen the threat.

In considering whether the disclosure is 'necessary' agencies need to consider whether the threat could be prevented or minimised in some other way that does not involve the release of sensitive or confidential information. The disclosure must be made to a person who can do something to prevent or lessen the threat. To address an imminent threat, the recipient would need to have the power to act urgently to achieve a tangible result in the particular case. A decision to disclose will only justify the disclosure of information that is necessary to prevent or lessen the threat. Agencies need to decide how much information needs to be disclosed. It may not be necessary for the whole file to be disclosed.

Current consensus is that breaching a patient's privacy to inform relatives that the patient carries a heritable genetic mutation and that they are thus at increased risk, would not meet the threshold for disclosure under the 'serious' and 'imminent' threat test. Whilst the threat of a heritable genetic mutation might be serious, it is very unlikely to be imminent.

Consider a patient with the HD mutation who did not want her minor children informed about their increased risk: not only is HD late onset, and thus not an 'imminent' threat to her children, there are also no interventions available to 'prevent or lessen' the threat to a potential sufferer's life or health, and thus disclosure cannot be justified by rule 11(2)(d) of the HIPC.

Consider the case of a patient with breast cancer caused by a BRCA1 mutation, who does not want her minor daughters informed of the heritable mutation: while there may be interventions available which might prevent or lessen the threat to her daughters' health, including increased surveillance or prophylactic surgery, the threat to her daughters is not 'imminent,' because breast cancer is also an adult-onset condition, with age-related penetrance.

Elger and Harding have suggested that children cannot be informed, against parental wishes, that they are at risk of being carriers of or affected by a late-onset heritable genetic disorder on the basis of a parent's affected status because 'the possibility of influencing reproductive decisions has so far not been included as a sufficiently grave reason for breaching confidentiality'.[8] In terms of disclosing increased risk for carrier status, there is also the difficulty of meeting the threshold of serious harm to the health or life of an individual: the health or lives of unconceived children or future individuals are not covered by the disclosure exception.

2.1.4 Common law exceptions

The common law duty of confidentiality that health professionals owe their patients can be breached on similar grounds as those outlined in the HIPC, and also where such is necessary in the public interest. Quite apart from whether the person's privacy rights would be breached, would a health agency or professional be breaching the confidentiality of a patient if a minor was informed (without the consent of those affected) that someone in her family carried a heritable genetic mutation that she too may be at risk for?

> *The [public interest] defence applies when other compelling public interests outweigh the confidentiality concerns. To determine its application, it is necessary to identify the public interest arguments for and against the specific disclosure, and then to 'weigh' those arguments in order to judge where the overriding public interest lies. … The need to prevent imminent harm is one important public interest of this kind that can trump confidentiality … The categories of 'public interest' that may trump a duty of confidence are not closed.*[9]

It is arguable that there is a compelling public interest, and at the very least a public health interest, in people at risk for serious heritable disorders (particularly those that can be prevented, mitigated or managed with surveillance or early detection) being informed of their increased risk as soon as possible. Arguably, there is also public interest in parents not withholding this kind of information from their children and thereby perhaps contributing to the likelihood of their suffering poor health or even early death in the future.

2.1.5 A duty to warn?

It is questionable whether a health professional who is aware that a minor is at increased risk for a heritable disorder which could be prevented or more effectively managed with surveillance or early detection would be held to have any '*duty* to warn' the minor (as opposed to a *discretion*).

> *… a duty to warn a potential victim of a patient's harmful conduct is only likely to be recognised in New Zealand as an aspect of the law of negligence when two essential criteria are met: there is a close degree of proximity between the victim-plaintiff and the health professional concerned; and the weight of the policy considerations supports the imposition of liability in the particular case. A sufficient degree of proximity must exist between the plaintiff and the defendant for a duty of care to be imposed. … The policy arguments must also favour imposition of a duty of care ... One important factor is whether omissions, rather than actions, on the part of the defendant are in issue, as liability for omissions is less readily imposed. A second is the fear that health professionals will be placed under an indeterminate form of liability to an indeterminate class. This second*

factor counts overwhelmingly against the imposition of a duty to warn the public at large, although excessive exposure to liability is obviously less of a concern when a threat is made to a single person or to a discrete class.[10]

On this basis it is perhaps conceivable that a duty to warn family members of increased risk for a heritable genetic mutation may exist (more so than a duty to warn people about potential violence from a patient.) The class of people who may benefit from such a warning is a discrete identifiable group, some of whom the health professional may indeed have a therapeutic relationship with also. Additionally, if the heritable condition in the family involves a fully or near fully penetrant mutation, such as those for HD or FAP, the predictability of harm arising at some stage will be greater than the predictability of a patient's violence. However, the threshold may not be met in respect of conditions (such as HD) for which no prophylaxis or medical treatment exists.

Both this issue and the issue of breaching confidentiality in the pubic interest are more general issues potentially affecting all people at risk for heritable genetic disorders and not just minors, and so cannot be discussed further here.

Health professionals can encourage parents to inform their children of their increased risk for a heritable genetic mutation, but it will only be in rare circumstances that they will be in a position to inform the minors themselves, without unlawfully infringing the privacy of the parents.

2.1.6 Access to personal health information

Minors are generally entitled to access any information held by any agency about themselves, pursuant to the Privacy Act 1993, and any health information, in particular, pursuant to rule 6 of the HIPC 1994. This would cover any medical notes or record of any discussion about whether or not a minor should have a genetic test, and the outcomes of any such discussions (including any test results if they had been tested.)

2.1.7 Disclosure exceptions

There are disclosure exceptions:

Privacy Act 1993

29. Other reasons for refusal of requests –

(1) An agency may refuse to disclose any information requested pursuant to principle 6 if –

(a) The disclosure of the information would involve the unwarranted disclosure of the affairs of another individual or of a deceased individual; or

(c) After consultation undertaken (where practicable) by or on behalf of the agency with an individual's medical practitioner, the agency is satisfied that –

(i) The information relates to that individual; and

(ii) The disclosure of the information (being information that relates to the physical or mental health of the individual who requested it) would be likely to prejudice the physical or mental health of that individual; or

(d) In the case of an individual under the age of 16, the disclosure of that information would be contrary to that individual's interests.

2.1.8 Disclosure involving unwarranted disclosure of the affairs of another individual

The commentary to the HIPC acknowledges that

> *… sometimes that information is inextricably linked with information about another person. Mixed information – that is information about two or more people – may be created through the use of joint counselling sessions or because one person has referred to another in the course of treatment. If the information cannot be separated out, agencies need to decide whether releasing the mixed information to the requester would involve an unwarranted disclosure of the affairs of the other person. Essentially, s 29(1)(a) requires agencies to strike a balance between the privacy interests of the requester and the other person.*
>
> *Some issues that might need to be considered are:*
>
> - *the nature and sensitivity of the information;*
> - *the nature of the relationship between the requester and the other person;*
> - *the likely reaction of the other person to the disclosure;*
> - *the other person's views about giving access (if known or able to be ascertained);*
> - *whether there are competing public interests warranting disclosure.*

There are two branches to this exception to the general rule of access to one's own health information: the information must be about the affairs of another person; and disclosure of the information must be unwarranted ('not justified' or 'without good and sufficient grounds.')[11]

> *This rule applies particularly to 'mixed' information: that is, to situations in which information about two or more people is bundled together such as when it concerns the relationship between them. Information is not mixed in this sense when it is not about the person making the request at all, however, but only about their immediate family members. There is no right of access to that material under rule 6 …*[12]

> *… the effects its disclosure may have on the service's ability to gather similar information in the future, must be weighed against the patient's needs to obtain access to all information upon which important decisions about their position may be made …*[13]

It is difficult to gauge the implications of this exception in the context of information about a heritable genetic condition within a family. Judging by the commentary to the HIPC, prepared by the Privacy Commissioner, it does not appear that shared genetic information was envisaged when section 29(1)(a) of the Privacy Act 1993 was drafted.

Deciding whether to refuse to disclose information concerning a familial genetic risk pursuant to section (29)(1)(a) would involve a balancing act: the health professional must balance the minor's individual right to access information about her own health against the parents' or other relatives' rights to confidentiality of their own health information.

When a minor is seeking information about the possibility of increased risk for a condition for which there is a family history, and discussions have taken place between the minor's parents and health professional in the past about risk status, the health professional may disclose the minimum amount of information necessary to the minor to enable a decision to be made on the information, while protecting the confidentiality of the other family members. However, clearly, it would be difficult to separate the information out. If the minor is to consider genetic testing in light of the information learned from the health professional, the minor would need to be fully informed of the risk status in order to make an informed choice (see right 6 of the Code of Health and Disability Services Consumers' Rights). This would necessarily involve the disclosure of information about the parents' genetic risk status, as this impacts directly on the minor's own risk status.

In terms of the factors that the health professional would need to weigh up (as suggested by the HIPC Commentary), the information may be considered highly sensitive, relating as it does to the patient's (and other of her relatives') current and future health. The relationship between the minor and the parents must be taken into account, as must the likely reaction of the parents if their child was informed about increased risk for a heritable genetic mutation, on the basis of their health information without their consent. Again, public health interests in prevention or early detection may also be relevant.

The issue of to whom the genetic information belongs becomes particularly pertinent in this kind of situation. However, as mentioned above, this kind of situation might also arise between other family members, or adult children and their parents, and thus is not an issue uniquely related to minors: as such it will not be discussed further here.

Even if a health professional did not refuse to disclose information about familial genetic risk to a minor on the basis of section 29(1)(a), might the minor be refused access to such information on one of the other grounds in the Act?

2.1.9 Sections 29(1)(c) or (d) of the Privacy Act

The HIPC Commentary gives the following guidance to health professionals in respect of refusing to disclose health information to a minor under the age of sixteen years:

> *Individuals, whatever their ages, are entitled to access their personal health information. If releasing information to an individual under 16 would be contrary to that person's interests, consider whether all of the information must be withheld, or whether part of it could be released without prejudicing their interests. It may be possible to release part of the information, or to summarise or rephrase it so that its release would not be as prejudicial.*

Dawson comments in respect of section 29(1)(c) that:

> *To permit information to be withheld on this ground the likely prejudice to the individual's health should be so significant and probable that it outweighs their usual right to obtain information about their health. … But there is not much evidence that providing patients with access to their medical records is likely to cause them harm. On the contrary, showing patients their records is now recognised as a useful way to discuss with them their condition and treatment, and a good way to keep them informed.*[14]

A similar threshold is arguably also required when refusing a minor's request for access to health information pursuant to section 29(1)(d) of the Privacy Act 1993: certainly the same rationale, in terms of limited evidence of harm and the benefits of open communication, is applicable The standard for refusing to disclose is lower, and less clear, in respect of those under sixteen years of age, than that for others: disclosure may be refused if such is merely against the minor's 'interests,' and not just if it is likely to prejudice physical or mental health. The threshold for withholding health information from minors on this basis may be considered a paternalistic anachronism and becomes less justifiable the older they become.

If a minor is competent to make health-care decisions, which may be the case if the minor is in a position to ask for health information, then the *Gillick* principle, the Code of Rights, UNCROC, the Privacy Act 1993 and HIPC, all of which emphasise respect for the autonomy of competent individuals, support the right to access health information. If a minor under the age of sixteen needs to access the information in order to make an informed medical decision, and is competent to do so, then the minor must be given all of the relevant information necessary to make that decision (right 6, Code of Rights).

If a minor were too young to play any part in health-care decisions, then it is difficult to envisage the minor seeking to access information. In the rare cases in which such a situation might arise, the health professional must still consider the minor's rights as a health and disability services consumer under the Code of Rights, and under article 12 of UNCROC, in particular; as well as considering the general thrust of privacy regulation which emphasises the rights of individuals to their own health information.

Would information that a minor was at increased risk of suffering a heritable genetic mutation be against the minor's interests? The answer to this question will depend upon the specific circumstances of the case. If the minor were at increased risk for a condition like FAP, then it would usually be in the minor's interests to know, given that surveillance and early detection can prevent or minimise much of the potential harm that may arise from the mutation. If the minor were at increased risk for HD, because a parent had tested positive for the HD mutation, then arguably it may not be in the minor's interests to know, given that the condition is late onset, and untreatable. However, studies on informing children of genetic risk, and the benefits and harms of genetic testing of minors considered earlier, indicate that there is so much more to perceptions of risk and harm than merely whether or not a condition is early or late onset, or treatable or non-treatable. The individual's personal strength and family situation will usually be very relevant. Perhaps if a minor is having to seek information about genetic risk status from a health professional, without the consent of the parents, then the minor may not be in a very supportive environment and the health professional will need to take this into account when deciding whether to refuse to disclose any increased genetic risk pursuant to section 29(1)(d) (particularly as a person's mood before genetic testing, and their family environment, seem to play an important part in predicting their reaction to their genetic risk status).

Even if a minor were not refused access to information about genetic risk status, on the basis of one of the exceptions considered earlier, how would the minor know to seek access to any such information if the parents had not disclosed the fact of a familial heritable illness?

2.2 Disclosure from parents

2.2.1 Do parents have a legal obligation to inform their children that they are at risk for a heritable genetic condition?

Parents are not agencies covered by the Privacy Act 1993 or the HIPC: they are not similarly obliged to provide their children with all relevant information held about them. If parents do not tell their children of genetic risk in their family, then minors are in a vulnerable position (as health professionals appear to have no duty and probably no discretion to tell them either, without consent).

In the main, because of the high value placed on autonomy in New Zealand generally, and particularly in our medico-legal system, others are not entitled to know about a family member's genetic risk status, or genetic condition, even where such knowledge would yield information about their own health. However, parents have far greater legal duties and responsibilities in relation to their children than people or family members have to each other generally. If parents (knowingly or recklessly) did not inform a child of her increased genetic risk status, when a failure to do so could result in serious harm or even death could they be held criminally responsible?

2.2.2 Section 152 of the Crimes Act 1961: Failing to provide the necessaries

Crimes Act 1961

152. Duty of parent or guardian to provide necessaries –

(1) Every one who as a parent or person in place of a parent is under a legal duty to provide necessaries for any child under the age of 16 years, being a child in his actual custody, is criminally responsible for omitting without lawful excuse to do so, whether the child is helpless or not, if the death of the child is caused, or if his life is endangered or his health permanently injured, by such omission.

The necessaries of life include medical care, and it is clear that if parents failed to seek life-saving treatment for a minor under the age of sixteen years they could be held criminally responsible for failing to provide the necessaries of life.[15] Increased risk for a childhood or early onset disorder might threaten a minor's health or life. In this case the parents would more likely be held responsible (if at all) for not seeking a potentially life-saving test (and the necessary sequelae) for the minor, rather than for not informing their child of the increased risk and leaving it up to the child to seek testing if so desired, because they are generally responsible for their child's well-being and life until the age of sixteen (evidenced by the duty to provide the necessaries of life to those under the age of sixteen).[16]

An omission to inform an asymptomatic minor of a heritable genetic mutation for a late-onset condition may endanger health or life later in adult life but section 152 of the Crimes Act does not apply to these circumstances; it aims to protect minors under the age of sixteen. Section 152 would also not apply to a failure to disclose increased risk for carrier status, or a failure to disclose increased risk to an *untreatable* late-onset disorder, as in neither case would the minor's life or health be endangered by the omission.

2.2.3 Section 145 of the Crimes Act 1961: Criminal nuisance

The Court of Appeal noted in *R v Lunt* that there is a common law duty on parents to protect their children from harm, which may extend further than simply providing the

necessaries of life. Blanchard J stated that 'a parent's common law duty is undoubted', citing *Russell on Crime* (12th ed.) London: Stevens & Sons, 1964, pp 402–3:

> *… parents are under a legal duty to take all reasonable steps within their power to preserve the lives of their children and this responsibility attaches to them automatically by virtue of their parenthood.*[17]

On this basis, it is arguable that parents could be held liable in criminal nuisance, pursuant to section 145 of the Crimes Act, for omitting to discharge their common law legal duty to 'take all reasonable steps within their power to preserve the lives of their children', if they failed to inform them that they were at increased risk for a heritable genetic mutation.[18]

> ***145. Criminal nuisance –***
>
> *(1) Every one commits criminal nuisance who … omits to discharge any legal duty, such act or omission being one which he knew would endanger the lives, safety, or health of the public, or the life, safety, or health of any individual.*

The phrase 'any legal duty' has been interpreted to include 'uncodified duties recognized by the common law'.[19] However, there are a number of problems with arguing that a parental failure to inform a minor of her increased genetic risk would result in a criminal nuisance pursuant to section 145 of the Crimes Act.

The exact scope of a common law parental duty to preserve the lives of children needs to be defined. It is unclear whether a duty to inform one's child of increased risk for a heritable genetic mutation would even fall under a common law duty to 'preserve the life' of one's child. There is the undeniable competing interest of the parent's own health information privacy, an interest which may not be present or as compelling in other life-preserving situations. A number of other factors might also be relevant – not least, whether medical interventions would be available, upon receipt of the information regarding one's increased risk, that could reduce or eliminate the likelihood of harm.

Regardless, any common law duty of parents to 'take all reasonable steps within their power to preserve the lives of their children' would almost certainly extinguish when guardianship ends (eighteen years, section 28, Care of Children Act 2004), or earlier. The duty may end at the age of sixteen in New Zealand, given that sixteen is the age at which the statutory duty to provide the necessaries of life ceases; minors can give their own consent to or refusal to consent to medical treatment (section 36(1), COCA 2004); and minors can challenge their parents or guardians' decision in Court (section 46, COCA 2004). Thus the threat of a criminal sanction pursuant to section 145 of the Crimes Act could not be relied upon to encourage parents to inform their children of their increased risk for a late-onset disorder.

Therefore, even if a common law duty of 'preservation of life' that included a responsibility to inform children of any increased genetic risks did attach to parents, it is unlikely that such a duty would survive past the child's sixteenth or eighteenth birthday (meaning it would generally not cover disclosure of increased risk to late-onset disorders). Additionally, to be liable, the parents would have to know that omitting to inform their children of their increased risk 'would endanger … the life, safety, or health' of their children. This criterion would not be met in respect of failing to inform a minor of increased risk for carrier status, which does not threaten life, safety or health. It would also not be met by failing to inform a minor of increased risk for an unpreventable and untreatable disorder.

Are there any other legal duties incumbent upon parents that might include a duty to inform their children of a heritable genetic mutation in the family?

2.2.4 Section 156 of the Crimes Act 1961: Duty of people in charge of dangerous things

The case of *R v Mwai*[20] involved a man charged with criminal nuisance (pursuant to section 145, Crimes Act) as a result of having unprotected sex with women without disclosing that he had HIV. He was found to be in charge of a dangerous thing (seminal fluid carrying HIV) in respect of which he had a legal duty to take reasonable care to avoid endangering human life, pursuant to section 156 of the Crimes Act.

> ***156. Duty of persons in charge of dangerous things –***
>
> Every one who has in his charge or under his control anything whatever, whether animate or inanimate, or who erects, makes, operates, or maintains anything whatever, which, in the absence of precaution or care, may endanger human life is under a legal duty to take reasonable precautions against and to use reasonable care to avoid such danger, and is criminally responsible for the consequences of omitting without lawful excuse to discharge that duty.

Hardie Boys J stated that 'the expression "anything whatever", coupled with the adjectives "animate or inanimate", is one of deliberately wide import.'[21] He referred to the Court of Appeal's decision in the case of *R v Turner*:[22]

> *The section has long been construed as including things that are not inherently dangerous but are dangerous if operated without reasonable care. … It is difficult, and indeed unnecessary, to disassociate a thing from its use. So the section contemplates both a thing inherently dangerous in its static condition or a thing dangerous in the course of its operation. … The phrase 'anything whatever' has, in our view, been deliberately chosen as a phrase of wide import. This is emphasised by 'whatever'. The only qualification to the phrase is that to be within the section it must be 'anything whatever' which, in the absence of precaution or care, 'may endanger human life'.*[23]

The word 'endanger' in sections 145 and 156 means to 'put in peril of something untoward' (per Tompkins J in *R v Turner*[24]). The Court held in *R v Turner* that it was not necessary for the prosecution to prove that danger to life was actually caused as a result of a breach of the duty. It was sufficient to prove that the acts or omissions put an individual or a member of the public in peril or at risk.[25]

In respect of the causal connection between the person's act or omission and the imperilment of life, the Court of Appeal said in *R v Mwai*:

> *It is not necessary in law for a particular act or omission to be the sole cause of the damage or injury in question. It is enough that it is a substantial cause. The evidence in respect of A is that her infection could have been derived only from intercourse with the appellant. It was the virus present in his semen that infected her. Her bodily mechanisms enabled the infection to occur. But without him it would not have occurred. He was a substantial cause of the infection.*[26]

A decade later, Dalley was charged with breaching section 145 of the Crimes Act because he failed in his legal duty to inform a woman, with whom he had had protected sex, that he had HIV.[27] The Police argued that despite the condom use the defendant had an *obligation to disclose* that he had HIV: he should not have exposed the woman to any risk that she had not accepted.

The Judge found that Dalley was in control of a dangerous thing (again, seminal fluid carrying HIV) and that he did have a legal duty to take reasonable precautions so as not to endanger human life. However, Judge Thomas considered that while most people would want to be told that a potential sexual partner was HIV-positive, and that there may be a moral duty to disclose that information, there is a difference between a moral duty and a legal duty. The legal duty in this case was to take reasonable precautions against, and use reasonable care to avoid, transmitting the HIV virus (para 43).

> *The evidence was that, so far as public health needs are concerned, the steps necessary to prevent the transmission of HIV can be met without the requirement for disclosure. In other words, the use of a condom … is considered sufficient. …*[28]

> *The duty under s 156 is to use 'reasonable' precautions and care. The duty is not to take fail-safe precautions. Reasonableness is an objective standard. On the basis of the evidence, I find that in the circumstances Mr Dalley did take reasonable precautions and care.*[29]

The Judge ruled that there did not have to be a significant risk of harm for the duty to take reasonable precautions to apply.

The words of s 156 are clear. Where anyone has under his charge or control anything which, in the absence of precaution or care, 'may endanger human life' he is under a legal duty to take reasonable precautions against and to use reasonable care to avoid such danger. There is nothing in those words which implies that there must be a significant risk of the danger.[30]

2.2.5 *Could the section 156 duty in respect of dangerous things apply to parents who omitted to provide their children with information about a heritable genetic mutation in the family?*

Whether parents could be considered to have a legal duty in respect of a dangerous thing, which they might be at risk of breaching if they did not inform their children of their increased genetic risk (due to a heritable genetic mutation in the family) would depend on a number of factors: whether information about a person's genetic risk status could be considered a 'dangerous thing'; whether parents could be said to be 'in charge' of the genetic information; whether parents omit to take reasonable care against or use reasonable care to avoid danger to human life; whether parents know that omitting to inform their children of increased genetic risk could endanger the life or health of their children; and whether they have a lawful excuse for the omission.

Section 156 explicitly applies a duty of care to persons in charge of 'anything whatever, whether animate or inanimate' that may endanger human life. It is unlikely that information that a person is at risk for a heritable genetic mutation would be covered by this section, primarily because while awareness of the information could potentially help to save or prolong a human life (by allowing for prophylaxis or early detection and intervention where such was available), the information itself cannot endanger human life, which is the only qualification on the deliberately wide choice of words. It is the genetic mutation that endangers life, not the information. Consider *R v Mwai* in which it was the seminal fluid containing the HIV that was the 'dangerous' thing' and not Mwai's knowledge and non-disclosure of his HIV. And whilst the parents could be argued to be in charge of the information, it does not make sense to speak of their being in charge of the genetic mutation.[31]

For the sake of argument, if information that a person was at risk for a heritable genetic mutation were classed as a 'dangerous thing' for the purposes of section 156, there would be no need for actual harm to be caused in order for the duty to be breached. Thus even if the person never developed the disorder that they were at risk for (whether because the condition was not fully penetrant or the person prematurely died) the duty may still have been breached by a failure to inform. And while the cases of *R v Mwai* and *Police v Dalley* highlight that there can be different means of taking reasonable precautions in respect of a dangerous thing – in the case of HIV, wearing a condom, *or* informing potential sexual partners of one's HIV status

– the only step that can be taken to reduce the danger to human life when a person is at risk for a heritable genetic disorder is to inform the individual at risk of the risk, so that the individual can take whatever preventive measures are available, and be alert for symptoms in order to begin any available treatment as soon as possible.

There is also a knowledge requirement in section 145 of the Crimes Act 1961. So, still assuming that information that a person was at risk for a heritable genetic mutation could be classified as a 'dangerous thing,' parents would have to know that omitting to take care with the genetic information (ostensibly by way of informing their child of her risk status) 'would endanger … the life, safety, or health' of the child. Parents might know that not informing a minor that the minor is at risk for the FAP or BRCA1 mutation, for example, would endanger health and life (assuming that they had been appropriately informed of the heritable nature of the genetic mutation that they were affected by or carrying). However, it would not make sense to speak of parents knowing that a failure to inform a child of the risk of being a carrier or of developing an unpreventable and untreatable disorder would endanger her health or life: because it would not. Carrier status does not endanger one's own life, and nothing could be done to avoid the danger to health caused by an untreatable late-onset disorder.

The clumsiness of applying the duty to various genetic testing scenarios reinforces the view that information that one is at risk of a heritable genetic mutation is not a 'dangerous thing' for the purposes of section 156 of the Crimes Act. The heritable genetic mutation is the dangerous thing, and parents are not in control of the mutation. They would also presumably have the lawful excuse of protecting their own health information privacy.

The section 156 legal duty of care in respect of 'dangerous' things does not appear to apply to information that an individual is at risk for a heritable genetic mutation. Parents are not compelled by this section to inform their children of their risk status. Are there any other potential legal duties parents might be subject to in respect of informing their children that they are at risk for a heritable genetic mutation?

2.2.6 Section 157 of the Crimes Act 1961: Duty to avoid omissions dangerous to life

Section 157 of the Crimes Act places a duty on people to avoid omissions dangerous to life:

> ***Section 157 – Duty to avoid omissions dangerous to life:***
>
> *Every one who undertakes to do any act the omission to do which is or may be dangerous to life is under a legal duty to do that act, and is criminally responsible for the consequences of omitting without lawful excuse to discharge that duty.*

Prima facie, the terminology of this provision fits better with the scenario under discussion: A parent may *undertake to do any act* – e.g. impart information – *the omission to do which is or may be dangerous to life* – an omission to impart the information may be dangerous to life e.g. if a person is not told that they are at risk for a heritable genetic mutation for which there are risk-reducing initiatives available (e.g. FAP or BRCA1).

However, there obviously needs to be a specific 'undertaking' to impart the information. Such an undertaking can be implied or explicit,[32] although it is unlikely that the undertaking parents implicitly make to protect their children would suffice, particularly as parental legal obligations to children are covered by section 152 of the Crimes Act 1961 and other legislation.

> *The section may overlap with some of the earlier provisions of this Part of the Act, but is aimed at cases not falling within them, in which there would be no legal duty apart from the undertaking.*[33]

Perhaps if parents made an undertaking with their health professional that they would inform their child by a certain time of the risk of a heritable genetic mutation, and that there was genetic testing available, the legal duty in section 157 would arise. However, consider the implications: how would the health professional know whether the parents had abided by the undertaking (without risking breaking confidentiality to find out)? What action would the health professional take if the parents breached the undertaking? He or she would still be subject to privacy regulation and the duty of confidentiality owed to the parent(s); the only recourse would appear to be going to the Police to report the breach of undertaking.

However, the health professional would still be bound by the confidentiality he or she owes to the parents not to disclose their health information without their consent, unless there was a 'serious' and 'imminent' threat to the health of another. This threshold would not be met in the case of a minor being at risk for carrier status or an untreatable disorder, and the 'imminence' test is also unlikely to be met in the case of increased risk for a late-onset disorder for which there is prophylaxis or treatment available (see discussion earlier).

Notwithstanding, approaching the Police about a breached undertaking which may endanger human life is not the most conciliatory way to work with the family to help them inform their child of her increased risk, and may well damage the relationship irreparably.

Moreover, one can only be criminally responsible for breaching the duty to avoid omissions dangerous to life, when one has breached the duty 'without lawful excuse'. Parents who breached an undertaking to inform their children of a heritable genetic

mutation in the family might argue that they had a lawful excuse – protecting their own health information privacy.

Thus, section 157 of the Crimes Act does not appear to apply to the situation where parents do not inform their children of their increased risk to a heritable genetic mutation.

Additionally, persons are only criminally responsible for the consequences of omitting to discharge one of the legal duties discussed 'if, in the circumstances of the particular case, the omission or neglect is a major departure from the standard of care expected of a reasonable person to whom that legal duty applies in those circumstances' (section 150A, Crimes Act 1961). Thus in either of these scenarios (suggested by sections 156 and 157 of the Crimes Act) successful prosecution would require proof that the parents' omission to inform their child of the heritable genetic mutation in the family was a major departure from the standard of care reasonably expected. Genetic testing, and predictive genetic testing in particular, is relatively new: it is unclear whether a parent's failure to inform the children of their increased risk of a heritable genetic mutation would be classified as a major departure from the standard of care expected of a reasonable person with that duty, in those circumstances. This may very well depend upon the type and level of risk involved and the opportunity for interventions.

Note that while an omission to discharge a legal duty could result in criminal nuisance if the person knew that an individual's life, safety or health would be threatened by the omission (section 145, Crimes Act), such an omission could also potentially result in culpable homicide if a person died as a result of such an omission (section 160(2)(b), Crimes Act). The intricacies of establishing a culpable homicide charge cannot be outlined in this report. Suffice to say that even if, pursuant to the Crimes Act, parents could be said to have a legal duty to inform their children of a heritable genetic mutation in the family for which there is prophylaxis or treatment available, it is very improbable that the causal nexus of an omission to inform and the death of the child would be sufficient to constitute culpable homicide.[34]

Thus, while parents may be under a moral duty to inform their children of heritable genetic mutations when their children are adults; when there is no likelihood of serious harm or risk to life or, notwithstanding, there are no useful interventions available; or when the condition is late onset, there do not appear to be any legally recognisable duties requiring this type of disclosure (except where such is necessary to prevent permanent injury to the health of or save the life of a minor under the age of sixteen, section 152 Crimes Act 1961).

2.3 Studies on informing children of heritable genetic mutations

> *… we often do not know what risk information gets discussed, the manner in which these conversations take place, or the impact they may have on family members' feelings, thoughts, and health behaviors.*[35]

Parents are naturally distressed by knowledge that their children are at risk for a heritable genetic mutation, and may want to delay telling them as long as possible. Several surveys have catalogued attitudes as to the appropriate age at which parents should inform their children that they are at risk for a heritable genetic mutation. Some may prefer never to tell. Others prefer to introduce the child or adolescent to the issues gradually, over a period of years. Some want to tell their children of their genetic risk status before they become sexually active, so that they can make informed contraceptive and reproductive choices. Conversely, some want to avoid telling their children at puberty, which is viewed as a time of life that is tumultuous enough as it is.

2.3.1 Attitudes

Whitelaw et al.[36] surveyed sixty-two people with the FAP mutation as to their views on the most suitable age at which to inform children about the FAP risk in the family. Of the fifty-one participants who responded to the question, twenty indicated that ten years of age was appropriate. A further thirteen suggested that between the ages of thirteen and fourteen was the most suitable time. Just three respondents thought that a child should be informed below the age of ten, and one thought that the information should be deferred until the child was over fourteen. The remainder indicated a suitable age somewhere between eleven and fourteen.[37]

> *There was a widespread feeling among the interviewees that children should not be told about polyposis until they were 'old enough to understand'. Most parents considered between 10 and 12 years to be the most appropriate age to introduce the subject, as they did not feel it was fair to 'spring' the diagnosis at the often emotionally turbulent time of puberty. However, it is interesting that 58/62 (93%) wished to test their children at birth and withhold this information from them for a decade.*[38]

Rosen et al. surveyed paediatric residents as to their attitudes towards dealing with the familial risk raised by a four-year-old boy presenting with Fragile X (among other clinical scenarios). Fragile X is an X-linked disorder, which generally means that only males fully express the disorder. Some female carriers of the Fragile X mutation can also be affected, but they are usually unaffected carriers. The vast majority of the residents (89 per cent) recognised the need to inform the boy's sister of the heritable pattern of the disorder: 31 per cent indicating it would be appropriate to do so at the

girl's current age of nine, and 86 per cent indicating it would be appropriate to do so by the teenage years.[39]

Elger and Harding surveyed medical and law students from six Swiss universities about their attitudes in respect of genetic testing of minors. All the students received an introduction to fundamental issues of medical law and ethics, including a presentation on informed consent, competence and confidentiality. They also received some information about HD and watched a fifteen-minute video interview with a thirty-eight-year-old woman who had recently been diagnosed as suffering from HD. The video informed the students that the woman had two sons aged ten and sixteen and that she was adamant that she did not want them told about or tested for HD at the moment.

Three quarters (75 per cent) of the medical and law students thought that the sixteen-year-old son should be informed of his mother's HD, despite her wishes; and 91 per cent indicated that he should have the chance to be undergo predictive testing for HD if he wanted.[40] Most of the comments in respect of whether or not the sixteen-year-old son should be informed of the mother's HD were to qualify agreement with the statement. For example, 'the question needs to be discussed with parents', and 'inform if the adolescent is sufficiently mature'. Some students, particularly medical students, were concerned about the psychosocial harm that might result from informing the adolescent. Those opposed to informing the adolescent raised related concerns: it is the parents' decision to inform; the adolescent is not mature enough to be informed; and psychosocial harms might result from informing him.[41]

2.3.2 Experience

Hallowell et al. noted that existing research on genetic risk disclosure within families indicated that few parents disputed the need to disclose risk information, but that they often found it burdensome (in terms of to whom, how, when and what to disclose). Biologically and emotionally close relatives were more likely to be informed of a hereditary risk than other relatives.[42]

Hallowell et al. interviewed seventeen men (five carriers, twelve non-carriers) who had been tested for a BRCA1/2 mutation in relation to communicating with their children about genetic testing. They also interviewed eight partners of the men (of three carriers, five non-carriers), and four daughters of non-carriers. The parents saw it as their responsibility to inform their children that they were undergoing genetic testing and of the results, rather than the health professional's responsibility. They wanted to deliberately manage the timing and content of the information disclosed.[43]

In choosing a communication strategy, they weighed up their children's rights to know about the hereditary risk, versus their own need to protect their children from anxiety-provoking information (roughly, half of the children were minors, and half were adult children). By the time of the interviews all parents had informed their children of the genetic testing undergone and the results, except for one solo father who wanted to tell his seventeen and nineteen-year-old children that he carried a BRCA mutation, but did not know how to explain it to them.[44]

Three different communication strategies were recorded, from the interviews: complete openness; limited disclosure; and total secrecy. Very few families were completely open with their children from the beginning regarding the fact of their father undergoing genetic testing for a BRCA mutation. None of the parents involved the children in the decision regarding whether or not to undergo testing, however, a few of the parents told their children that their father was undergoing testing as soon as the decision was made. The majority of the parents opted for limited disclosure: either making brief reference to or downplaying the testing before the father was tested, or not informing their children until after the father had received his test results. A small group of parents kept the father's involvement in testing a closely guarded secret, until after the fact (and indeed one father, mentioned earlier, had not informed his children of his result either).[45]

The age of the children played a part in the choice of communication strategy: those families with children under the age of eighteen were more likely to opt for limited disclosure about the implications of a mutation positive result or keep the father's involvement in testing a secret. However, some parents also opted for limited disclosure in respect of adult children, particularly where their children were emotionally fragile or in more vulnerable circumstances (such as pregnancy).[46]

Two of the fathers felt that their chosen strategy had been problematic. One father who was completely open indicated that as a result the whole family was very anxious whilst awaiting the results. Another father, who had kept the testing completely secret, expressed regret because he now did not know how to inform his children of his carrier status.[47]

Likewise, parental attempts to limit disclosure or maintain secrecy were not always appreciated by their children. Children who were unaware of any hereditary risk were shocked when their fathers informed them that he carried a BRCA mutation. Some children expressed resentment and felt that they should have been informed before their father underwent testing, one claiming that 'her parents' secrecy had compromised her ability to control knowledge about her risk status'. Other children were unsure about the meaning of the test results, and some of the daughters of non-carriers were still concerned about increased risk of developing breast cancer.[48]

However, it must be acknowledged that while parents may have been more reticent about discussing genetic testing and its implications with adult sons and younger children (< 18 years) prior to receiving the result, nearly all of the children had been informed about their father's test result by the time these interviews took place. Thus, while age may have affected the type of disclosure strategy adopted, it did not appear to have affected disclosure per se. This observation supports earlier research which found that breast cancer patients feel it is their duty to inform their children of their cancer risks, whatever their age. However, it must be borne in mind that only 8/16 fathers in the present study had children under the age of 18 at the time of the interview. Given the small numbers involved, it is difficult to draw conclusions about the effect of children's age on disclosure patterns.[49]

Hallowell et al. concluded with some implications for clinical practice: solo parents and their children might need more support through the genetic testing and counselling process; parents needed to be encouraged to think about what their children's disclosure preferences might be; and adult children (particularly children of non-carriers) might receive incomplete information about the implications of genetic test results.[50]

Skirton conducted a study with fifteen individuals from families affected by HD: twelve parents with adolescent or young adult children at risk for HD, and three adults at risk for HD who had parents in the cohort.[51]

Families at risk for or with affected members with HD viewed the condition very negatively, feeling that it was a curse and that they could not envisage anything worse. Only one individual interviewed had heard of HD prior to a diagnosis being made in a close family member, indicating that communication was generally poor among family members (as subsequent enquiries frequently revealed other affected family members). Skirton suggests that the lack of communication partly contributed to the shock experienced by families when they received the diagnosis or heard the news. A period of mourning also followed diagnosis, focusing on loss of quality of life, of a personal future and of peace of mind. Some children also suffered the loss of the ability to depend upon a parent for warmth and security, 'amounting almost to the loss of childhood itself'.[52]

There was evidence that children were distressed about the suffering they observed in their parents or grandparents in eight different families, and in the opinion of several subjects, this distress was exacerbated by the lack of explanation of the cause of the suffering.[53]

All of the participants felt that parents should be the people to inform their children of the condition within the family. It was acknowledged that a lack of skill might

make this less feasible in some cases and that disclosure assistance and support for the parents could be sought, generally from health professionals.

> *Whether parents intend to tell their offspring about the risk of genetic disease is related not only to their attitude toward the condition, but also to their belief in the inherent right of an individual to information which has important personal implications.*[54]

Only one of the twelve parents interviewed had formed an intention not to tell her children of their risk. Skirton suggests that for the other eleven parents, the belief that their children should know of their risk 'was obviously a stronger force than the fear of telling'. The mother who did not intend to tell her daughters (who were all over eighteen) was the woman quoted earlier (at 'Disclosure of familial genetic risk to a minor') who acknowledged that she might be over-protective. One of her daughters was interviewed and expressed her frustration and anger that her mother was hiding and controlling information that should have been shared.[55]

All of the three 'child' participants stated that adults ought to be given information which may affect their future. Those who felt that information had been purposefully withheld from them were deeply resentful and angry and felt disempowered. Resentment was only enhanced by motives for delaying disclosure that included concern that children might not find an accepting partner or be able to have children: 'those at risk considered that future partners had every right to be aware of the genetic risks before making long-term commitment'.[56]

There was no consensus as to the best time to disclose genetic risks, with opinion as to the age at which children were mature enough and able to comprehend the information ranging from eight to eighteen. A number of participants indicated that it might be easier for a young person to absorb the news than an older person because of the distance of time between the person's current age and the age at which they might become affected by the condition. Parents generally considered it important to inform the young person before they had children of their own, with some considering it necessary when their children became sexually active, and others when their children were in serious relationships.

> *The advantages of telling a child gradually as the opportunity presents itself or as questions arise was stressed by a number of respondents, who felt that there were benefits in being able to absorb the information slowly and so gradually adjust to the altered potential of life.*[57]

The available evidence suggests that people tend to be in favour of informing their children of their genetic risks, and of informing them themselves, rather than via a health professional. It is, however, obviously a delicate and often difficult task, and the ages vary at which parents consider disclosure appropriate.

2.4 Reasons to disclose genetic risks to minors

Analogous research from parents with HIV or AIDS reveal that reasons given not to disclose their status to their children included: the child's perceived inability to understand information about HIV/AIDS; fear of a negative reaction (fear or sadness); and concern about feelings of rejection towards the parent. Reasons to disclose their status to their children included: not wanting their children to find out from someone else; and not wanting to keep family secrets. The parents who did not want to disclose their HIV status to their children reported more depression and less family cohesion.[58]

Factors affecting parental decisions to share personal medical information, including genetic test results, include: the characteristics of the illness; the child's characteristics; and parental characteristics. Whether there are prophylactic or treatment strategies available for the parent (or child) may affect disclosure, as might the appearance of symptoms. Adolescents are usually given more information about family health risks than younger children, and parents may be more likely to disclose such information to children who are well-adjusted, rather than those with adjustment difficulties. Parents who exhibit greater distress post counselling are apparently more likely to disclose their test results to their children.[59]

The advantages of disclosure of genetic test results to children include: parental and child emotional relief, better ability to prepare for the future, and modelling of open communication behaviour. The disadvantages of not disclosing include: child anger at not being informed of the hereditary risk sooner; modelling of family secrets; and a mistaken belief that no familial health risks exist.[60]

The adolescent and young adult participants in Skirton's study indicated that they had been aware of secrecy concerning the differences in an affected parent and the family as a whole, and the causes of those differences.

> *… explanation of the reasons for the difficulties can help the child or young person to make sense of the situation and begin to adjust. It may be of some reassurance to parents that none of those at risk felt there were any disadvantages to being told the truth.*[61]

Skirton suggests that an individual's adjustment to being at risk of a disease and 'renegotiation' of the future may take place most successfully if the person is given time and support to work through 'the renegotiation process' at their own pace. One of the participants commented on the benefit of having time to adjust to her new risk status before adulthood, and compared her situation favourably against the difficulties faced by a friend who had not been informed until adulthood. The parents who had shared the news of the familial risk immediately with their teenagers also

reported that their children had seemed to cope well, possibly because the family could support each other and adjust to the news together.[62]

Malpas argues that children should be informed of familial genetic risks because:[63]

- Informing children respects their developing autonomy and decision-making abilities.
- Not informing them until late adolescence or early adulthood might shatter the future that 'they have begun to create and envisage for themselves'. Minors approaching adulthood will already have made some life plans, perhaps some career decisions, or they may have significant partners and be contemplating having children.
- Younger children may more readily accept and adjust to the information.[64]
- Keeping family secrets is harmful: 'Long experience demonstrates that hiding information from children usually does not work and that efforts to keep secrets leave children feeling deceived and abandoned'.[65] Keeping information from children about their genetic risks exerts power over them and withholds power from them.
- Informing children removes their uncertainty, particularly where family members are exhibiting signs of disease.
- Children are able to understand information about heritable genetic risks, and they are often aware of family tensions without necessarily knowing the cause. 'We simply cannot assume that children are not capable of understanding genetic knowledge or that they are better off not being told when they have experienced the consequences of genetic conditions within their families.'[66]
- Children benefit from knowing their biological origins and identity.[67]

Where there is a serious genetic disorder within a family, children will often be more aware of it than adults may think. Clarke offers a useful analogy between handling genetic information about children and handling information about adoption.

> *Both categories of information are likely to be unwelcome but withholding the information from the child for ever is likely to cause further problems. The practical issue becomes how best to impart the relevant information…. Not to mention that there is important information until suddenly broaching the topic with an unsuspecting teenager is not likely to be the most successful approach – and many teenagers will not in fact be totally unsuspecting …*
>
> *Most children ask questions about their origin and their family that allow some information to be imparted at an early age even if it is just the fact that there is more information to be imparted later. It will usually be unhelpful to mislead a child even if the full facts are not disclosed at once. Gradually increasing quantities*

of information can be given … as the child increases in maturity. In the case of adoption …the child is able to seek out his/her natural parents once they have decided for themselves that they want this information. In the context of genetic information, it is possible for the adolescent or young adult to seek genetic testing once they have decided for themselves that they want this information. In both contexts, it is possible for the family to have explained that there is a potential 'genetic' problem for the child to consider once older … and full control over this process can be given explicitly to the adolescent as a way of helping him/her to terms with the possibly unwelcome information.[68]

Minors may also be exposed to genetic information via the media, the internet, in school, or through family contact or involvement with a support group.

… apparently trivial events in adolescence or youth, such as family visits or reading articles in a popular magazine, are shown as raising concerns long before any question of genetic risk had been formally reached; these events are recalled with clarity decades later.

Information about the existence or availability of genetic testing would also be instructive for the minor concerned about her genetic risk status. Research into the psychological and genetic counselling implications for adolescent daughters of mothers with breast cancer, found that less than a third of the daughters were aware of BRCA gene testing (compared to 82 per cent of the mothers), despite being significantly concerned about inheriting breast cancer.

The significant worry that adolescents with BC mother have about inheritable risk and the lack of communication between the mothers and daughters regarding genetic testing are considered the most important findings of the study. … there is a need for mothers and daughters to share information about heritable BC based on actual risk, whether low or high, rather than perceived risk particularly if the adolescent has overestimated their risk. … the results suggest the need for additional interventions to improve open and direct communication regarding genetic technology in these families as well as support for adolescent daughters in expressing their concerns regarding BC and genetic risk.[69]

2.5 Comments

Health professionals generally cannot inform a minor about a heritable genetic condition in the family without the permission of the person from whom the health information was gleaned (particularly without an explicit request for the information from an at-risk minor). And yet parents are under no legal duty to inform their children of heritable genetic conditions within their families for which they may be at risk.

Whatever parents and guardians decide about informing their children of their genetic risks, the matter is currently unregulated. Parents can be advised by a health professional about an appropriate age and way in which to inform their children but families will make these decisions for themselves.

The available evidence suggests that people tend to be in favour of informing their children of their genetic risks, and of informing them themselves, rather than via a health professional. It is, however, obviously a delicate and often difficult task, and the ages vary at which parents consider disclosure appropriate.

3 DISCLOSURE OF GENETIC TEST RESULTS TO THE MINOR TESTED

Also problematic is the question of disclosure of genetic test results to a minor who has been tested on the basis of parental consent as a young child.

3.1 Disclosure from health professionals

The Code of Health and Disability Services Consumers' Rights (the Code) states that all health consumers are entitled to all of the rights in the Code, commensurate with their competence (where this is relevant). Regardless of whether a child is able to give legally valid consent, the child must be informed by the health professional, to an extent commensurate with their potential to understand, of the purpose of any tests and *what the test results are* (right 6(1)(f) and (g)). Where a child is tested as a baby or toddler this will be less feasible.

Issues around health professional disclosure of a minor's genetic test results to the minor may arise most often when a child has been tested for carrier status or for susceptibility to a late-onset condition. If a minor had been tested for a childhood or early onset condition, the minor will often have developed the disorder (or not, as the case may be) by the time it becomes clear that a genetic test may have been undertaken.

Because the minor, in this case, has actually been tested, and is not simply seeking information about risk status on the basis of other family members' health information, the concerns about privacy and confidentiality of others have less or no weight when a health professional is considering disclosing the minor's own test results. The conceptual issue of whose health information familial genetic information actually is, is also less salient, given that a discrete set of health information exists in respect of the minor who has undergone genetic testing.

The American Society of Human Genetics/American College of Medical Genetics Report *Genetic Testing in Children and Adolescents, Points to Consider: Ethical Legal and Psychosocial Implications* notes in particular that:

> *A request by a competent adolescent for the results of a genetic test should be given priority over parents' request to conceal information. When a younger child is tested and the parents request that the provider not reveal results, the provider should engage the parents in an ongoing discussion about the benefits and harms of the nondisclosure, the child's interest in the information, and when and in what manner the results should be disclosed.*[70]

Health professionals can encourage parents to inform their children of their genetic test result, and where they refuse to do so health professionals will be subject to fewer constraints in informing the minor themselves (compared to those outlined in respect of informing minors of increased risk based solely on familial genetic information).

3.1.1 A duty to warn?

A duty to warn may more readily be accepted in the context of a health professional who knows, as a result of genetic testing performed on a person as an infant or young child (perhaps for the FAP or a BRCA mutation), that a person is at a greatly increased risk for developing cancer. There will be a very close degree of proximity between the 'victim-plaintiff' and the health professional if the health professional continues to treat a tested minor on an individual basis as an adult. Policy considerations in this type of situation may tilt the balance in favour of imposing a duty: to inform a person of genetic testing undertaken as a child *if* the results indicated a significantly increased risk of developing a condition for which there are risk or harm-reducing interventions available.

Imposing such a duty of care would not be placing health professionals under 'an indeterminate form of liability to an indeterminate class'.[71] The class of person to whom such a duty would be owed would be discrete and clear: persons tested as children (on the basis of parental consent) for carrier status or increased risk for a late-onset disorder.

The extent of the duty would be less clear if the health professional no longer saw or had any contact with the person tested as a child: would he or she have a duty to warn any such person of their carrier status or increased risk for developing a late-onset condition?

In terms of predictability of harm arising: the likelihood of a person developing the condition, if they have the variation tested for, is certainly high in respect of some genetic variations e.g. those for HD, FAP, breast cancer (although note that BRCA penetrance is age-related). A positive carrier test would also mean that the person tested carried the mutation tested for (assuming the test results were interpretable and accurate) and was clearly at risk of passing the mutation on to any future offspring.

On the other hand, if a person tested positive as a child for an *untreatable* late-onset disorder, the public interest and policy considerations in favour of imposing a duty on health professionals to warn the person, as an adult, of their test result may diminish: there is nothing that the person tested or the health professional can do to minimise the likely harm. Additionally, as Dawson points out, liability for omissions, rather than actions, is less readily imposed.[72]

A duty to warn people about genetic tests they had as children has not been imposed upon health professionals in New Zealand thus far: unsurprisingly, particularly given that only relatively recently have advances in technology allowed predictive tests to be undertaken. Whether or not such a duty should be imposed may be a question better left for legislators than the judiciary: this will be discussed further.

3.2 Access to personal health information and disclosure exceptions

Minors are generally entitled to access any personal health information pursuant to rule 6 of the HIPC 1994. This right clearly extends to information such as genetic test results (see subclause 4(1), HIPC 1994).

3.2.1 Section 29(1)(a) of the Privacy Act 1993

Disclosing a minor's own genetic test results to her would not involve unwarranted disclosure of the affairs of another individual. The information is not mixed in this case, as it may arguably be in the case of shared familial genetic risk status. The minor's test results relate specifically to the minor: no balancing of another individual's rights or interests is required.

However, might a minor be refused access to her own genetic test results pursuant to one of the other more applicable grounds in the Act?

3.2.2 Sections 2 (1)(c) or (d) of the Privacy Act 1993

In respect of section 29(1)(c), at least, access to personal health information should only be refused by a health professional where 'the likely prejudice to the individual's health' is 'so significant and probable that it outweighs their usual right to obtain information about their health'.[73]

However, the standard for refusing to disclose is lower, and less clear, in respect of those under sixteen years of age than the standard in respect of others. Disclosure may be refused if such is merely against the minor's 'interests,' and not just if it is likely to prejudice physical or mental health. However, the same rationale that applies to section 29(1)(c) should apply to section 29(1)(d) regardless of the difference in terminology: the likely prejudice to the minor's *interests* should be so significant and probable that it outweighs the usual right to obtain health information. We have argued that a lower threshold for withholding personal health information from

minors may be considered a paternalistic anachronism and becomes less justifiable the older they become. Section 29(1)(c) should suffice in any case where serious concerns are held about the effect the information may have on the minor.

> *But there is not much evidence that providing patients with access to their medical records is likely to cause them harm. On the contrary, showing patients their records is now recognised as a useful way to discuss with them their condition and treatment, and a good way to keep them informed.*[74]

Would learning the genetic test results be against a minor's interests, or likely to prejudice physical or mental health? And to such an extent that the usual right to obtain personal information about health is outweighed? The answer to this question will depend upon the specific circumstances of the case. The benefits and harms of genetic testing of minors, including the benefits and harms raised by knowing that one is at increased risk for developing a disorder, or that one does not carry the heritable genetic mutation tested for, have been explored in great detail.

If the minor has tested positive for something like the FAP mutation, then it would almost certainly be in her interests to know, given that surveillance and early detection can prevent or minimise much of the potential harm that may arise from the mutation.

If a minor tested negative for any genetic variation then it would be more difficult to argue that such information would be against the minor's interests, or would prejudice physical or mental health. While negative effects have been recorded in respect of negative genetic test results, this is arguably less likely in the case of minors who have (given their youth) probably not spent the majority of their lives assuming that they had the disorder and consequently need to readjust to their new risk status. Survivor guilt may, however, be a possibility if one or more of the child's siblings or a parent suffers from the heritable mutation. However, as with making a decision under many of the other privacy rules, the exercise becomes a balancing act: on balance would knowledge that one did not carry a heritable genetic mutation be likely to be more beneficial or prejudicial to the physical or mental health of the individual concerned? It would be a rare case in which a minor would benefit more from not knowing that he or she did not carry a heritable genetic mutation.

If the minor had tested positive as a baby or a very young child for increased risk for a disorder such as HD, then arguably it may not be in the minor's interests to know, and the information may well prejudice mental health, given that the condition is late onset, and untreatable. The putative psychosocial harms of such knowledge are a large part of the reason why all of the professional position statements outlined caution against testing minors for late-onset conditions, and particularly for those that are untreatable.

It may be argued by analogy from our arguments on the benefits and harms of testing in respect of competent minors seeking genetic testing, that the fact that the minor is seeking to access the test results indicates a belief that the information will be more beneficial than harmful (and in such a case it may very well be). Perhaps the minor who requests access to genetic tests results is prepared for any result. However, competence is of vital importance in this respect: a minor who would not be competent to give informed consent to the genetic testing, for which the minor now seeks results, may be denied access to the results if they would be likely to prejudice the minor's interests or physical or mental health. The minor could not have chosen to undergo testing, because of the putative harms of such testing. However, if competent to make a decision about whether or not to undergo testing, then the minor should not be denied access to the test results (produced though they were on the basis of parental consent): given that the minor may make medical decisions. It would be nonsensical if a minor were considered competent to give informed consent to undergo testing and yet it were not considered prudent to pass on the results.

Additionally, it is not clear that the same benefits as those discussed earlier, in the context of competent minors who have requested genetic testing, would accrue to those who had been tested as a child, without a choice, on the basis of parental consent.

The 'right not to know' is intimately related to the right not to be tested. If a minor (or an adult) does not want to know about an increased risk for a genetic mutation then surely it is much better not to have been tested at all, than to be given a choice whether or not to access test results having been given no choice about whether or not to be tested. If the minor has already been tested on the basis of parental consent then other people know highly sensitive information that the minor may not know, may not wish to know and presumably would not wish others to know.

Whilst arguably the minor's competence and autonomy is enhanced and respected in making the decision about whether to access the test result, the minor's autonomy has already been infringed by testing without consent – there was no involvement in the original decision to elicit the information (by way of genetic testing). In effect the parents or health professional are saying, 'Now that we have made the decision to find out this sensitive information about you, would you like to know the information too?' This scenario may be considered more disempowering than empowering.

And while the minor may want to know the test result once aware that it exists, the minor may very well resent the parents for having undertaken testing: even more so if given a mutation-positive test result.

Studies on informing children of genetic risk, and the benefits and harms of genetic testing of minors, considered earlier, indicate that there is much more to perceptions of and actual risk and harm than merely looking at whether the condition tested for

is early or late onset, or treatable or non-treatable. The individual's personal strength and family situation will usually be very relevant. As discussed earlier, perhaps if a minor is having to seek information about the genetic test result from a health professional, without the consent of parents, then the minor may not be in a very supportive environment and the health professional will need to take this into account when deciding whether to refuse to disclose test results pursuant to section 29(1)(c) or (d).

3.2.3 Comments

Given the complexities, deciding whether or not to disclose a minor's genetic test result is going to require a careful case-by-case approach. Genetic counselling will be necessary if a minor is to be told about a mutation-positive result, and may be necessary regardless of the test result. If a minor is aware of having been tested for a heritable genetic mutation but is denied access to the test results both by parents and health professionals (all of whom presumably know the results), one can only guess the psychological harm this could induce. The concerns raised by disclosing the information, coupled with the concerns raised by refusing to disclose the information, support the argument that carrier or predictive genetic testing that is not clinically indicated should generally be restricted to those who competently request it, and generally not be permitted on the basis of parental consent alone.

Regardless of whether a minor is ultimately granted access to genetic tests results by the relevant health professional or agency, how would the minor know to seek access to her test results if her parents had not disclosed the fact that testing had taken place in the past?

3.3 Disclosure from parents

Parents will generally be aware of a child's genetic test results in accordance with the general law and policy relating to children and health privacy. The child's results will provide information about the parents' risk status (and paternity) too. Indeed, in most cases the parents will already be aware of their own genetic risk status because of the pattern of the heritable disorder within their family, which will often be the catalyst for testing a child.

So do parents have a legal obligation to inform their children of the results of genetic testing that they underwent when they were younger?

Parents are not agencies covered by the Privacy Act or the HIPC: they are not similarly obliged to provide their children with all relevant information held about them, or abide by the rules in respect of access to personal health information.

If parents do not tell their children that they underwent predictive genetic testing or carrier testing as a baby or very young child, minors are in a vulnerable position (as no duty to inform has yet been recognised in respect of health professionals who know of the test result). If parents do not inform their child of a genetic test then it is possible that the child may never find out (perhaps more so if the results were mutation negative), particularly if the family GP is not the same GP used as an adolescent or adult.

Similar issues arise as those discussed earlier in the context of informing minors about existing familial genetic risks. If parents (knowingly or recklessly) did not inform a child of the genetic test result, when a failure to do so could result in serious harm or even death, could they be held criminally responsible?

Section 152 of the Crimes Act 1961 imposes a legal duty on parents to provide necessaries for any child under the age of sixteen and makes them criminally responsible for omitting without lawful excuse to do so, if the death of the child is caused or if life is endangered or health permanently injured, by such omission.

The necessaries of life include medical care, and parents who fail to seek life-saving treatment for a minor under the age of sixteen can be held criminally responsible for failing to provide the necessaries.[75] A mutation-positive genetic test result might indicate a threat to a minor's health or life: but if that were the case then the parents would be more likely to be held responsible (if at all) for not seeking appropriate medical intervention as a result of the test result, rather than for not informing the minor of the result so that medical attention could be sought, because they are generally responsible for her well-being and life until she is sixteen years old.

An omission to inform an asymptomatic minor of a mutation-positive genetic test result for a late-onset condition may endanger health or life later in adult life but section 152 does not apply to these circumstances; it aims to protect minors under the age of sixteen. Section 152 would also not apply to a failure to disclose carrier status, or a failure to disclose increased risk for an *untreatable* late-onset disorder, as in neither case would the minor's life or health be endangered by the omission.

Could parents be held liable in criminal nuisance on the basis of section 145 of the Crimes Act 1961 if they omitted to discharge their common law duty to 'take all reasonable steps within their power to preserve the lives of their children',[76] by failing to inform them that they had tested positive for a mutation predisposing them to a condition, knowing that the omission would endanger their health or lives?

As with section 152, any such liability under section 145 would more likely attach for omitting to seek treatment for the minor where this was necessary, rather than omitting to inform the minor of test results – particularly if the minor were not

competent to give informed consent to necessary procedures or treatment upon receipt of the test result.

Even if a common law duty of 'preservation of life' that included a responsibility to inform children of genetic test results did attach to parents, it is unlikely that such a duty to preserve life would survive past the child's sixteenth or eighteenth birthday (meaning it would generally not require disclosure to a minor of increased risk for late-onset disorders to a minor). Additionally, omitting to inform their child of a positive test result for carrier status or increased susceptibility to an unpreventable and *untreatable* condition would not endanger life, safety, or health.

Similar difficulties as those discussed, in respect of the duty of people in charge of dangerous things (section 156) and the duty to avoid omissions dangerous to life (section 157), arise in the context of parental failure to inform their child of a genetic test result.

It is improbable that information about a child's genetic test result would be covered by the duty of people in charge of dangerous things (section 156 of the Crimes Act 1961), primarily because, while awareness of the information could potentially help to save or prolong a human life (by allowing for prophylaxis or early detection and intervention where such was available), the information itself cannot endanger human life, which is the only qualification on the deliberately wide choice of words. It is the genetic mutation that endangers life, not the information, and it does not make sense to speak of the parents being in charge of the genetic mutation.[77]

Additionally, even if information about a genetic test result were included in the category of 'dangerous things,' a failure to inform a child of mutation-positive test results in respect of *carrier status* or an *untreatable* disorder would not endanger health or life.

With respect to the duty to avoid omissions dangerous to life (section 157 of the Crimes Act 1961), an omission to impart a child's genetic test result to the child may be dangerous to life; for example, if the child is not told about testing positive for increased susceptibility to a heritable genetic mutation for which there are risk-reducing initiatives available (e.g. FAP or BRCA1).

However, liability pursuant to section 157 requires a specific 'undertaking' to impart the information, being a genetic test result in this case. Perhaps if parents made an undertaking with their health professional that they would inform their child of the genetic test result by a certain time, the legal duty in section 157 might arise. However, how would the health professional know whether the parents had abided by the undertaking, and what action would he or she take if the parents breached the undertaking? He or she would still be subject to privacy regulation and the duty of

confidentiality owed to the parent(s); the only recourse would appear to be going to the Police to report the breach of undertaking.

However, the health professional would still be bound by the confidentiality he or she owes to the parents not to disclose their health information without their consent, unless there was a 'serious' and 'imminent' threat to the health of another. This threshold would not be met in the case of a minor being at risk for carrier status or an untreatable disorder; and the 'imminence' test is also unlikely to be met in the case of increased risk for a late-onset disorder for which there is prophylaxis or treatment available (see discussion earlier).

Additionally, persons are only criminally responsible for the consequences of omitting to discharge one of the legal duties discussed 'if, in the circumstances of the particular case, the omission or neglect is a major departure from the standard of care expected of a reasonable person to whom that legal duty applies in those circumstances' (section 150A, Crimes Act 1961). Thus in either of the scenarios (suggested by sections 156 and 157 of the Crimes Act) successful prosecution would require proof that the parents' omission to inform their child of the genetic test result was a major departure from the standard of care reasonably expected. Genetic testing, and predictive genetic testing in particular, is relatively new: it is unclear whether a parent's failure to inform the children of a genetic test result would be classified as a major departure from the standard of care expected of a reasonable person with that duty, in those circumstances. This would most likely depend upon the type and level of risk involved and the opportunity for interventions.

A legal duty to inform one's child of the results of any genetic testing undertaken as a child does not sit comfortably with any of the existing provisions in the Crimes Act 1961. This is unsurprising given that such a possibility would not have been envisaged by the draftsmen of the day. Parents do not appear to be legally obliged to inform their children of their genetic test results, although they may of course be legally criticised for failing to act on information that would seriously threaten their health or lives (section 152 Crimes Act 1961).

In some cases, the test results may dictate the disclosure of the results. If the child tests negative for the heritable condition for which he or she was at risk, then it may be suitable to let the child know immediately to reassure the child, and then to reinforce the information at a later time when it will be retained as part of the medical history.[78]

Equally, if the child tests positive to a symptomatic diagnostic test or develops an early or childhood-onset condition shortly after testing, then the child will know that their health is compromised, and should be told why and what the implications are, in ways and to an extent commensurate with understanding. Having hypothesised

that childhood cancer survivors who had learned of their diagnosis at an early stage would tend to be better adjusted at follow-up than those who learned they had cancer long after the diagnosis was made, Slavin et al. studied 116 survivors on average twelve years after diagnosis.[79] They found that good psychological adjustment was associated with patients' early knowledge of the diagnosis, and that many of the survivors, their parents and their siblings felt that a cancer diagnosis should be shared with a child early on.

Even when test results are mutation negative (or perhaps mutation positive for a late-onset condition) parents may not want to inform their children for a variety of reasons ranging from paternity issues to concerns about the child's capacity to absorb and adapt to the information. Professionals may share these concerns.

The issue is perhaps most complex when a child tests positive for a predictive or probabilistic late-onset condition for which there are few or no known effective medical interventions. Where a condition has no known medical prophylaxis or management then it would be difficult to argue that disclosure would be justified on the basis that it avoids harm or has an actual benefit for the child.

Genetic counselling should explore all of these issues with parents and, where appropriate, children, to ensure that they are fully aware of the implications of genetic risks and genetic testing before any decisions are made. Counselling should also be available throughout and after the testing process.

3.4 Studies regarding informing children of genetic test results

3.4.1 Attitudes

An international study of professionals involved in genetic testing revealed that United States and United Kingdom geneticists were reasonably evenly divided on whether to wait until a child reached the legal age of majority to tell him or her about genetic test results (compared with 73 per cent of United States *primary care physicians* favouring telling a child before the age of majority). Generally speaking, fewer of the parents than providers would tell children test results before the age of majority (54 per cent for familial hypercholesterolaemia, and 47 per cent for cancer susceptibility).[80]

Only a minority (41 per cent United States, 20 per cent United Kingdom) of the geneticists would tell a minor about a test result indicating predisposition to alcoholism before the age of majority, while the majority of primary-care physicians (68 per cent) would inform a minor before that time. Most geneticists would also not inform children of the results of HD or Alzheimer's disease testing before the age of majority: just 12 per cent of United Kingdom geneticists would inform minors of either of the test results before majority, and amongst United States geneticists, just

20 per cent would inform a minor of an HD test result, and 18 per cent would inform about an Alzheimer's disease test result before majority (compared to 44 per cent and 46 per cent of primary-care physicians for the respective disorders). Just under a third (31 per cent) of parents would inform a minor of Alzheimer's disease results before majority, with 55 per cent deferring disclosing until majority, and 14 per cent indicating that they would never tell their child the test results.[81]

In a survey of attitudes of mothers of paediatric oncology patients, age was considered to be a determining factor regarding when mothers thought that healthy children should be told about (hypothetical) genetic cancer predisposition test results: 5 per cent favoured telling children under the age of seven years; 12 per cent would tell a child between seven and ten years; just over half (51 per cent) would tell a child between the ages of eleven and seventeen years; and a third (33 per cent) would not tell a child the test results until he or she was eighteen years old.[82]

3.4.2 Experience

Duncan's international study of professionals involved in predictive genetic testing found that, of the eighteen children under the age of fourteen who had undergone predictive tests for non-medical reasons, only two had been informed of their test results: both had tested mutation negative for the disorders for which they were tested.[83] There was some evidence of parental distress in three of the cases, which included anxiety about how and when to tell their child that they had tested positive for the HD or dystonia mutation.[84]

Jolly et al. interviewed people who had been carrier tested for balanced chromosomal translocations when they were young children. One of the young men tested was not informed of his carrier status until he was seventeen-years-old. He indicated that he would rather have been informed earlier 'because it's too much pressure on me now. I'd rather have had it over and done with at an earlier age'. Another young man said that he was glad that he had grown up with knowledge of his carrier status: 'Because if for instance I found out about it at the age of sixteen, it would have come as a huge shock. It probably would have affected me more than it already had … I think by that age you probably have certain ideas and certain plans and then you realise this and it stops those plans'. Jolly et al. note that while it is important to keep the knowledge of the genetic risk 'alive' in the family, children do not need to be tested to be aware of the issues.[85]

3.5 Comments

A minor who is seeking access to genetic test results, rather than information about risk status on the basis of other family members' health information, does not provoke the same the concerns for a health professional in respect of the privacy

and confidentiality of others. However, as with disclosing familial genetic risk, there currently exists *no legal duty to warn* a minor of her genetic test results.

Minors might be refused access to their genetic tests results pursuant to sections 29(1)(c) and 29(1)(d) of the Privacy Act 1993 if the information were considered prejudicial to their interests, or physical or mental health. Given the complexities, deciding whether or not to disclose a minor's genetic test result will require a very careful case-by-case approach. Genetic counselling will be necessary if a minor is to be told about carrying a genetic mutation, and may be necessary regardless of the test result. If a minor is aware of having been tested for a heritable genetic mutation but is denied access to test results both by the parents and health professionals (all of whom presumably know the results), one can only guess the psychological harm this could induce. The concerns raised by disclosing the information, coupled with the concerns raised by refusing to disclose the information, support the argument that carrier or predictive genetic testing that is not clinically indicated should generally be restricted to those who competently request it, and generally not be permitted on the basis of parental consent alone.

Parents do not appear to be legally obliged to inform their children of their own genetic test results: they are not covered by the Privacy Act 1993 or the HIPC or bound by any duties in the Crimes Act to inform their children of genetic test results, except where the results may seriously threaten their health or lives (section 152, Crimes Act 1961).

4 DISCUSSION ON DISCLOSURE OF GENETIC RISK STATUS OR GENETIC TEST RESULTS TO MINORS

We return to the questions posed at the beginning of this section: Should and, if so, when, how, what and by whom, minors be informed of their genetic risk status? These are difficult issues, and much of the relevant discourse will lie outside the mandate of legislators, regulators and policy-makers.

The HGSA Policy on *Predictive Testing in Children and Adolescents* makes the following recommendation in terms of informing children of hereditary disorders in the family:

> *Parents should be encouraged to make their child aware, at an appropriate age, of the genetic condition in the family and the implications, and for the child to be reared with this knowledge. Being able to discuss this information within the family over a number of years at different stages of maturity will ultimately enable the child to make a better informed choice about predictive genetic testing as an adult.*[86]

In terms of disclosing actual test results, the more general HGSA Policy on *Presymptomatic and Predictive Testing for Genetic Disorders* states that:

> *Where the risk status for a disorder has been established for a child, either prenatally or after birth, the child should be informed that the information will be available once he/she has reached a level of maturity consistent with understanding its implications.*[87]

It is important that when information is disclosed to a minor about her genetic risk, it is given appropriately so that the minor fully understands the information and is not unduly frightened.[88] Simply telling a young child that there is a heritable disorder within the family for which the child is at risk, and then never mentioning, discussing or developing the issue again, would not be of much benefit to the child. The message and its implications need to be reinforced.

> *Families that are dysfunctional and have trouble discussing personal information that impacts upon its members will no doubt have difficulty disclosing genetic information in an empowering way to young children. Adults who are pessimistic about their own genetic risk, who feel burdened by the disease, and who do not envisage a positive future for themselves or their children, may not communicate such risk positively or effectively with their children, if at all.*[89]

Malpas, Hallowell et al. and the evidence from studies involving parents with AIDS/HIV emphasise the importance of ensuring that parents are fully informed and are fully supported in terms of their own genetic risks or test results, so that they can in turn inform and support their children.

> *In addition to managing their own emotional responses and considering the medical implications for themselves, parents must also weigh the pros and cons of communicating this information to their children.*[90]

The findings of Skirton's study confirm that the adjustment of the family is not necessarily a function of time, but 'rather of the ability and willingness of the family members to "work through" the stages of grief … and to emerge with a personal model which allows them to invest in the future'.[91]

> *Families who considered themselves to be generally 'loving and sharing' felt they utilized these attributes to deal with the issues which arose after the diagnosis was made. Lyn, who felt her family was not 'sharing', seemed wistful at the opportunity which had been lost by the withholding of news. She felt frustrated that she had been denied the opportunity to make informed decisions and to support her parents through a difficult period.*[92]

4.1 Should there be a duty to disclose genetic risks to minors?

> *… from a young age children should be advised of the risks associated with knowing one's carrier status, even though the actual testing is postponed. Next to the responsibility of parents, genetic service providers should follow up the genetic risk of a family. It is important to avoid situations by which minors are never informed about their genetic risk. In addition, genetic counselling should be made available to minors throughout the course of their lives, with the aim of helping them envisage undergoing carrier testing.*[93]

One of the purposes of the Human Assisted Reproductive Technology (HART) Act 2004 is to establish a comprehensive information-keeping regime to ensure that people born from donated embryos or cells can find out about their genetic origins (section 3(f)). One of the HART Act's principles is that donor offspring should be made aware of their genetic origins and be able to access information about those origins (section 4(e)). Section 50 of the HART Act 2004 provides for access by donor offspring to information about donors: information must be provided if requested.

The Act thus recognises the importance of people knowing about or being able to access genetic information that affects them. However, children born of donor embryos or cells are in a similar position to children who are unaware of their genetic risk status or genetic test results: they may never know that the genetic information is accessible if they are not informed of this fact by their parents or a health professional. The HART Act 2004 provides no mechanism for *mandatory* disclosure of their genetic origins to children born from donated embryos or cells, and no mechanism for mandatory disclosure of any preimplantation genetic test (PGD) results to the child tested.[94]

Similarly, children who have been adopted can request access to their original birth certificates (pursuant to section 4 of the Adult Adoption Information Act 1985), but no one is obliged to inform them of the fact of their adoption. Adopted children are thus similarly vulnerable to the decisions of their guardians.

Public health and policy considerations might favour some form of duty to inform children of the existence of their own genetic test results over a duty to inform children about their genetic origins. With regard to genetic test results, the information to be disclosed belongs solely to the child tested; it does not concern the identification of someone else who may not want to be identified, as may information about genetic origins. Additionally, in many cases the genetic test result information will have been identified as having potentially health or life-threatening consequences if undisclosed.

4.2 Who would be covered by a duty to disclose genetic risk? Parents? Health professionals?

The evidence reveals that most people think that parents should be the ones to inform their children about genetic risk. A parental duty to inform children would also be in line with the evidence considered in the 'Benefits and harms' section: a minor's family environment, support networks and individual stability before testing seemed to be important predictors of the reaction to the result after testing. Similarly, an open and communicative family environment may reduce any psychological harm consequent upon a minor learning of increased risk for a heritable disorder. Learning of increased risk from her parents may be less traumatic than only discovering the status as a result of prising the information out of a health professional constrained by confidentiality obligations and privacy regulations.

However, the degree of State intervention necessary to monitor and enforce a positive parental duty to impart genetic information to children may not be feasible or desirable. Punitive provisions for failure to disclose the information may seem extreme, but a lack of sanctions might give any such duty the appearance of being a toothless tiger.

However, we believe that there should be some means by which minors (or adults) can be informed of the fact that they underwent genetic testing as children, particularly where they are at increased risk for the disorder for which they were tested.

4.3 Recommendation

A register should be established to facilitate disclosure to persons who have reached the age of sixteen or eighteen (or earlier if they are competent and personally seek access to the information) of the fact that they underwent genetic testing as children. The information initially disclosed may inform the minor either that predictive or carrier testing was undertaken as a child, or that some information is available about genetic risk status should the minor wish to access it (if disclosure of the fact of having been tested is considered to be too much unsought information for the first contact).

This notification could be achieved using a similar process as for notification of relatives about genetic testing for a familial disorder by the South Australian Familial Cancer Service (FCS).

As part of a study conducted by Suther et al.,[95] participants with a heritable mutation predisposing them to cancer gave the FCS contact details of close relatives who might be similarly affected.

The FCS sent a letter to each close relative. The timing of this letter was decided with the proband to allow for informal contact with relatives. Some probands were keen to contact their relatives informally, others agreed with reluctance, while others declined to do so and were relieved that the unit would notify their families. The wording of the letter was in general terms and did not identify … the familial cancer syndrome, mutation, or details of cancer risk (thereby reducing the potential for adverse impact on the recipient's insurability in Australia). … South Australian relatives who sought further information were offered an appointment; interstate relatives were directed to their local services. The FCS did not seek further contact with relatives who did not respond to the letter … (thereby avoiding the risk of harassing those who did not want information).[96]

Following is an excerpt from the letter sent by the FCS to relatives who might be at risk. A similar letter, imparting a similar degree of information (with the necessary changes, of course), could be utilised by a genetic test results register to disclose results to persons tested as children.

I am writing to you at the request of one of your relatives because they wish to share important health information with you. … A member of your family has been found to have an inherited tendency to develop cancer. This may mean that there is an increased chance of you developing cancer. Even if people have not developed cancer themselves, they can pass this inherited tendency to their children. If a person has an increased chance of developing cancer, there are effective ways of reducing this risk.

What can you do now?

We recommend that you discuss this letter with your doctor. We can provide your doctor with further information about the family's situation as well as assistance in managing your cancer risk. We also recommend that you discuss this matter with a counsellor at a genetics clinic.

A genetic counsellor can offer you:

***Assessment** about your chance of having this condition or of developing cancer.*

***Advice** to you and your doctor about managing your chance of developing cancer. …*

Please let us know if you would like to find out more about the services available to you by indicating your response on the enclosed form and sending it back to us. These services are available at no cost to you. Please be assured that the information we give you and any information we receive from you is treated confidentially.

> ***We urge you to take this matter seriously*** *as this information can be life saving.*[97]

We consider a genetic test results register established for this purpose to be the appropriate approach to ensuring that people who undergo testing as children are informed of the fact, because:

- It would encourage parents and health professionals to disclose test results to children – as the fact of testing will be disclosed to them anyway;
- It gives the person tested as a child the choice of whether or not to find out the information (assuming that he or she has not already been told); and
- It avoids the difficulties of imposing a new duty, which may have unwieldy and undesirable consequences in terms of monitoring, enforcement and sanctions.

The WHO *Review of Ethical Issues in Medical Genetics* made a similar suggestion.

> *It should not be assumed that parents would convey full and accurate information years after a test is performed (Fanos and Johnson, 1992. Parents have an ethical obligation to convey to children the results of such tests at such time that the child can understand and benefit from the information. Professionals have an obligation to establish information networks that may enable them to follow families as they move, so that the professional can recontact children when they reach adulthood in order to make sure that they receive their test results. In order to make recontact possible, the test results should be placed in the child's primary care record for the information of subsequent physicians.*[98]

Similarly, the United Kingdom CGS Working Party report on 'The genetic testing of children' proposed that:

> *Where testing may be of interest to the future adult, for health reasons or to permit informed reproductive decision making, the offer of counselling (and possible testing) should be made once the person is mature or in early adult life; this may require the establishment of an active genetic register.*[99]

Genetic counselling services would be required to assist any minors contacted through this process, in deciding whether or not to access their test result, and to support them whatever their choice.

And of course, the privacy of any such register and the information it contained would have to be strictly maintained.

We do not argue that a similar register be established to keep track of information about minors who are simply at increased risk for a heritable disorder but who have not been tested themselves. The issue of disclosure of familial genetic risk cannot

be resolved as neatly because it relates to all family relationships, and not just those between parents and their children. The implications are much wider than can be considered here. However, it is desirable that families do inform their children of familial genetic risks and let them make up their own minds about how to use the information (if genetic testing is not clinically indicated during childhood); health professionals should encourage parents to do this.

5 CONFIDENTIALITY AND PRIVACY

This section focuses on what kind of privacy protection a minor who is considering undergoing genetic testing, or one who has been tested on the basis of parental consent, might expect

5.1 Parental access to their children's health information

5.1.1 Disclosure one of the purposes for collection

While it has been argued that parents do not have an automatic right to information about their children, because the Privacy Act and HIPC (along with other rights-based legislation) draw no real distinction in terms of their application to children and adults,[100] health professionals are generally presumed entitled to disclose medical information to a child's parents where they require the consent of the parent to the proposed treatment. It is important that parents are aware of their child's condition and its medical implications so that they can be completely involved in the medical treatment: disclosure of the health information is one of the purposes for which it was collected, and is thus permitted under rule 11(1)(c) of the HIPC (although note that 'facilitating informed consent does not necessarily involve disclosing the child's entire medical records').[101]

In cases where the need to disclose information is anticipated at the time of collection of the information, it is as well for practitioners to inform children or young people that disclosure is one of the purposes for which the information is being collected. For example, a child might be told that the information gained from a medical examination will be used for the purpose of gaining her parents' consent to a procedure or treatment. 'The Code does not require consent to be obtained for these anticipated disclosures: it is purpose-driven, not consent-driven.'[102]

The Code of Health and Disability Consumers' Rights also gives parents who are consenting on behalf of their children rights: to effective communication; to be fully informed; and to make an informed choice and give informed consent. The right to be fully informed includes the right to information about the results of tests and procedures (right 6(1)(f) and (g)).

If parental consent is not required in order to advise or treat a child (e.g. a competent minor), then disclosure of information cannot be made to the parents on the basis that this was one of the purposes for which the information was collected, or on the basis of the rights given to consumers' parents by the Code of Rights (as the parents are no longer 'entitled to give consent on behalf of' the minor if a competent minor chooses to make personal medical decisions). This is discussed further later.

5.1.2 Section 22F of the Health Act 1956: Disclosure and refusal to disclose

Section 22F of the Health Act 1956 requires information to be disclosed to representatives (a parent or guardian in respect of a child under the age of sixteen) on request. 'The central aim of section 22F is therefore tolerably clear: to promote the sharing of information in order to assist ongoing treatment. … The apparent intention … is to deem someone who is legitimately seeking health information … for the purposes of further treatment, to stand in the shoes of that patient.'[103]

However, there are grounds that health professionals can rely upon in order to withhold a child's health information. Requests for information can be refused when there is a lawful excuse not to disclose, or when refusal is authorised under the Privacy Act or the HIPC. Rule 11(4) of the HIPC authorises the refusal of a representative's request where: the disclosure of the information would be contrary to the minor's interests (rule 11(4)(b)(i)); where the agency has reasonable grounds for believing that the minor does not or would not want the information disclosed (rule 11(4)(b)(ii)); or there would be good grounds for withholding the information under Part 4 of the Act if the request had been made by the individual concerned (rule 11(4)(b)(iii)).[104]

A classic example of disclosure of health information to parents being contrary to a minor's interests (rule 11(4)(b)(i)) might arise where evidence of abuse has been discovered and it may not be in the minor's interests, at that time at least, for such to be disclosed to the parents, who may be the abusers. There are many obvious examples of when a minor might not wish her parents to know her health information (rule 11(4)(b)(ii)) in the sexual health field.

In the context of genetic testing most of the exceptions to disclosing pursuant to section 22F of the Health Act 1956 are more applicable to competent minors, rather than minors who have been tested on the basis of parental consent. Otherwise, one might well question the rationale of undertaking genetic testing on the basis of parental consent, if the test results were not going to be disclosed to the parents (whether because such is deemed contrary to the minor's interests, the minor does not want the results disclosed or for some other reason). If parents, who are charged with making medical decisions for their children not competent to make their own decisions, are not informed of and thus cannot act on the basis of the test results, the information may

stagnate, given that no one is in a position to give informed consent to any procedure or treatment related to the information. A situation such as this should not arise after the family has undergone genetic counselling in respect of the proposed testing.

5.1.3 Disclosure would be contrary to the minor's interests

Disclosure may be contrary to a minor's interests where some harm would arise from the parents knowing the information, in this case a genetic test result. Perhaps the parents would withdraw from a child, or at the other extreme smother a child, who tested positive for the HD mutation, for example. However, such would be a reason for *not testing* the child in the first place on the basis of parental consent, rather than not informing the parents of the test result.

In respect of a competent minor under the age of sixteen, disclosure may be contrary to the minor's interests for the same reasons: parents may withdraw or may treat their child as overly vulnerable because of the test result. However, if a minor is competent to have made the decision in respect of genetic testing, then the second exception permitting refusal of information to a parent is more relevant. Given that the minor is competent to make the decision, it should be up to the child whether or not the information is disclosed to her parents.[105] In such cases, the decision should not be based upon the more paternalistic exception regarding the minor's interests.

5.1.4 Reasonable grounds for believing that the minor does not or would not wish the information to be disclosed

In the case of a competent minor under the age of sixteen who did not want the parents to have access to genetic test results, health professionals would have a clear mandate to refuse a representative's request for information pursuant to rule 11(4)(b)(ii), HIPC. Health professionals should check with the minor before disclosing or refusing to disclose the information to parents on the basis of this provision.

If the withholding grounds do not apply, the information must be disclosed on request pursuant to section 22F of the Health Act 1956. If the withholding grounds do apply, the information may still be disclosed because reliance on the withholding grounds is discretionary (section 22F(2)).

> *Disclosure under rule 11 is discretionary. Health professionals cannot be required to disclose simply because one of the exceptions applies. Disclosure in accordance with rule 11 may not be allowed by some codes of ethics, so health professionals should check their ethical duties before relying on an exception in rule 11.*[106]

Disclosure and privacy issues should be canvassed thoroughly in genetic counselling and clinical discussions prior to any genetic testing taking place, so that all parties have a clear idea to whom what information may be disclosed, and upon what grounds, before the decision whether or not to undergo testing is made.

5.2 Privacy issues when a minor has been tested by parental consent

Parents may want to use a child's genetic information, gained from genetic testing, to have other children of theirs tested. This is a legally permissible use of their child's information. Regardless, where pre-symptomatic or carrier testing is undertaken, parents would probably have the same cause to have all of their children tested, given the existence of the heritable genetic variation in the family.

Additionally, parents may choose to tell other family members of their child's test results to warn them of their own risk. A child's parents are not bound by the Privacy Act 1993 or the Health Information Privacy Code 1994 to keep their children's health information private. This places children in a uniquely vulnerable position. While adult patients can, to a large extent, control the risk of their health information being disclosed by choosing to whom they disclose the information, the ability of a child to control the use or disclosure of her own medical information is severely curtailed to the extent that her parents will generally be in receipt of the information and not bound by any confidentiality duties in respect of it.

Whilst it can commonly be assumed that parents usually do not mean their children harm by discussing their health information, they may generally disseminate the information however they choose; for example, to the child's school, the child's friends, their own friends, sports coaches and employers. The child patient's lack of control over the information, in terms of the parents' knowledge and freedom of dissemination, could have negative impacts in the future, including social, employment and insurance discrimination. Such information must, therefore, be handled sensitively given that the results may turn out to have harmful effects for the child as an adult.

Interestingly, Johnson et al. note that, '[i]n most cases, adults with chronic conditions were less likely to disclose private medical information than were parents of children with the same conditions.'[107] This suggests that adults are more protective about genetic information when it relates to themselves rather than to their children.

Privacy protection is also of greater concern in genetics than in other branches of medicine as family members and relatives have a greater interest in knowing the information; and the information gained can be predictive, unlike other medical information that might be revealed about a child. For example, the fact that a child had her tonsils out is unlikely to be of much relevance to anyone or any agency in the future, as compared with the fact that a child has a significantly increased susceptibility to a cancer. Although some commentators object to 'genetic exceptionalism', McLean suggests that:

> *… in many ways, the diagnosis of a genetic disorder, or even of carrier status, is different from the diagnosis of other conditions because the ramifications of the diagnosis go far beyond the individual concerned. …While health-related information is generally regarded as being an inherently private matter, and the confidentiality of diagnostic information is usually jealously preserved by doctors, tensions may emerge when the traditional principles of medical ethics are tested in genetic disorder cases.*[108]

Apart from discussion and possibly mediation there is, however, very little that a child can legally do to prevent the parents disseminating the child's personal information, which may include genetic status.

Traditionally, in order for a breach of confidence action to be made out, the information must: 'have the necessary quality of confidence about it'; have been imparted in 'circumstances importing an obligation of confidence'; and there must have been 'unauthorised use of the information'.[109] The requirement that the information needs to have been 'imparted in circumstances importing an obligation of confidence' has been subsequently eroded in the United Kingdom.[110]

Dawson has noted that a breach of confidence action may arise from third party disclosure of confidential information:

> *The duty of confidence may also cover third parties to the therapeutic relationship to whom information has been disclosed, when they have actual knowledge this information is confidential, or they ought reasonably to know, or they have turned a blind eye to the matter.*[111] *That the information was not 'innocently acquired' is therefore not a defence in such cases. So, where medical information is mistakenly delivered to the wrong person, for example, it should not be disclosed to unauthorised people if its confidential character is plain.*[112]

A duty of confidentiality has not yet been recognised in respect of the unique relationship between parents and their children. A myriad of issues would be relevant if such a duty were recognised; such issues will not be discussed here as the duty does not currently exist.[113]

A tort of invasion of privacy has recently been recognised in New Zealand.[114]

> *It is actionable as a tort to publish information or material in respect of which the plaintiff has a reasonable expectation of privacy, unless that information or material constitutes a matter of legitimate public concern justifying publication in the public interest. Whether the plaintiff has a reasonable expectation of privacy depends largely on whether publication of the information or material about the plaintiff's private life would in the particular circumstances cause substantial offence to a reasonable person. Whether there is sufficient public concern about*

the information or material to justify the publication will depend on whether in the circumstances those to whom the publication is made can reasonably be said to have a right to be informed about it.[115]

And with respect to children in particular:

… we consider that the criteria for protection, requiring private information in respect of which there is a reasonable expectation of privacy the publicising of which would be highly offensive, provide adequate flexibility to accommodate the special vulnerability of children. … Of course, the vulnerability of children must be accorded real weight and their private lives will seldom be of concern to the public.[116]

The tort currently only appears to cover *publication* of private information and thus would presumably not apply to a mother disclosing her child's genetic test results to a friend. However, Dawson notes: 'It is not entirely clear … how wide the publicity given to private facts must be. If only a few key people would have been informed, would that constitute unwarranted publicity at all, or would it be relevant only to damages?'[117]

Privacy issues are similar to those raised by an adult who has been tested and does not want to share her results with the family; but they are complicated by the fact that in the adult's case there are self-determining decisions which can be made. Decisions made on behalf of a child can best be described as 'other regarding' rather than 'self regarding' and for that reason the child may be more vulnerable to disclosure of information which the child might have preferred (had they been in a position to express a view) to have maintained in confidence. The broader, more general issue of whether health professionals should be entitled or obliged to breach confidentiality (or whether private individuals should be legally obliged) to inform family members and relatives of a familial genetic risk cannot be canvassed to any great degree in this section of the report, in which the primary focus is on genetic testing of children.[118] Suffice to say, in most cases parents will be aware of their children's test results as a matter of course, and can seemingly treat that information as their own information for the purposes of disclosure. Health professionals are of course bound by confidentiality duties to the child patient and may not disclose his or her results except to those entitled to receive them (usually the parents) or pursuant to one of the statutory or regulatory exceptions discussed.

5.3 Should there be legal restrictions to prohibit parents from disclosing their children's health information?

Again, as with imposing a duty on parents to disclose genetic test results to minors, we are concerned about the enforceability, monitoring and any punitive mechanisms attached to such a duty. However, a duty of confidentiality may be more readily

enforced than a duty to disclose information *to* minors: the agency charged with enforcing the duty can take a reactive role once unwarranted disclosure has been made, rather than the more proactive and interventionist role required to police disclosure to the minor.

However, the child's privacy interests need to be weighed up against the interests served by allowing parents to disclose their child's genetic test results to certain people or agencies (e.g. school or caregivers so that they can be alert for early symptoms) and the parents' rights to freedom of expression (section 14, New Zealand Bill of Rights Act 1990).

The lack of a parental duty of confidentiality and the difficulties raised by the imposition of such a duty provide another strong argument against genetic testing of children upon the basis of parental consent.

A general rule against genetic testing of children coupled with rigorous genetic counselling emphasising the need to inform the child of the genetic test result, and the need to keep the information private, may be the most effective way to safeguard the child's overall interests: rather than permitting testing and trying to police the sequelae.

Given the interest that a child has in maintaining the privacy of the genetic test results, where genetic testing of a minor is undertaken on the basis of parental consent (whether because it is clinically indicated or, more rarely, it is not clinically indicated but nonetheless deemed to be in the child's best interests), parents should be made fully aware of the implications of disclosing their child's genetic test results to others; encouraged to consider how the child might feel about disclosure as an adult; and encouraged to maintain the child's privacy wherever possible.

5.4 Competent minors and privacy

> *Teenagers rate confidentiality as one of the most important aspects of medical care as it underpins future relationships with professionals and is based on mutual trust.*[119]

Competent minors are entitled to the same confidentiality as adults. As outlined earlier, the predominant reason for disclosing a child's medical situation and records to her parents is the need to seek informed consent for treatment. If parental consent is not required in order to advise or treat a child, such as in the case of a competent minor, then disclosure of information cannot be made to the parents on the basis that this was one of the purposes for which the information was collected (pursuant to the Privacy Act or the HIPC), or on the basis of the Code of Rights (as discussed).

Parents do not have an automatic right to all information about their mature children. The Code does not draw a distinction between children and adults, and essentially adopts an understanding-based test for the ability to exercise rights under it. Just as the views of a mature young person must be listened to and taken into account in respect of treatment, so should their views be ascertained and considered in respect to disclosure of personal information.[120]

5.4.1 Privacy Act and HIPC exceptions

Where there is no statutory authority or requirement to disclose health information (see earlier discussion on section 22F of the Health Act 1956), then health professionals must consider whether any of the exceptions in rule 11 would allow disclosure; and whether they want to disclose (given that they are not required to).[121]

Relevant exceptions include:

Disclosure is to the individual's representative where the individual is … unable to exercise his or her rights (rule 11(1)(a)(ii)).

Kerkin states that 'it should not be assumed a child cannot exercise his or her rights simply because of his or her age. Understanding and maturity are relevant to the ability to exercise rights'.[122] A minor who has been afforded genetic testing on the basis of competent informed consent would also be capable of exercising the right to privacy.

The disclosure is authorised by the individual or the individual's representative where the individual is … unable to give his or her authority (rule 11(1)(b)).

Similarly, Kerkin argues that if the disclosure has not previously been discussed with the child, then the child could be asked to authorise it, and that it 'should not be assumed that a child cannot grant an authorisation simply because of his or her age'.[123] Again, if informed consent to testing has been given the child would also be able to grant or refuse authority to disclose.

Disclosure is one of the purposes in connection with which the information was obtained (rule 11(1)(c)).

If a health professional intended to disclose a minor's genetic test result to the parents, and this was one of the purposes for which the test was undertaken (perhaps to assist the parents to support their child, or to give them more information for future reproductive decisions), then this aim would need to be disclosed to the minor before testing was performed.

The health agency believes on reasonable grounds that it is either not desirable or not practicable to obtain authorisation from the individual concerned and the information is disclosed … to the principal caregiver … of the individual … in accordance with recognised professional practice and the disclosure is not contrary to the individual's or representative's expressed request (rule 11(2)(b)).

> This seems particularly applicable to situations involving young children who would not be competent to give an authorisation and where recognised professional practice would be to deal with the parents or guardians.[124]
>
> This exception is directed at allowing health professionals to disclose health information about a patient to someone who is involved in caring for the person and may have to make decisions for that individual. It accords with the guardians' rights in the Code of Rights regarding information and consent, and the general common law and statutory guardianship rights in respect of medical decision-making for minors. However, it would not generally apply in respect of competent minors, given that breaching their privacy would not be in accordance with professional practice, and may be contrary to the minors' express request. The consent of the minors would need to be sought before disclosure: generally pursuant to rule 11(2) of the HIPC, and also pursuant to the requirement that disclosure not be against their express request.

The health agency believes on reasonable grounds that it is either not desirable or not practicable to obtain authorisation from the individual concerned and the disclosure is necessary to prevent a serious or lessen a serious and imminent threat to the life or health of the individual concerned or another individual (rule 11(2)(d)).

> This exception would become relevant, for example, where a minor refuses disclosure of the information to a parent (or another) when the minor's life or health, or the life or health of another, is in serious danger.

Harm to self– If a minor tested mutation positive for a condition for which there were beneficial medical interventions available, such as the FAP mutation, but refused to adopt any interventions, the serious and imminence test may be met. However, health professionals would still need to consider: seeking the minor's consent for disclosure (rule 11(2)); whether the threat could be lessened in any other way not involving the disclosure of sensitive personal health information; disclosing only to a person or persons who may be able to prevent or lessen the threat (this may not always be the parents, particularly if the minor has undertaken the entire genetic testing process alone); or disclosing only the information necessary to prevent or lessen the threat (rule 11(3)). Also, the HIPC Commentary recommends that 'the purpose of the disclosure should be made clear so that the person receiving the information knows the limited purpose to which it can be put', so that the recipient of the information does not take a *carte blanche* approach to dealing with it.

The criteria for disclosure would not be met under this rule in respect of unpreventable and untreatable disorders because the threat could not be prevented or lessened. However, disclosure may be permitted where the health professional believes that the minor may or has become depressed as a result of a genetic test result, or is engaging in self-harming or suicide ideation. Again, the health professional should consider discussing disclosure with the minor before disclosing, to ascertain how the minor feels about disclosure and what the likely response might be. However, ultimately the health professional must make the judgment whether to disclose or not.

Harm to others – This issue has been discussed earlier in the context of informing competent minors of their genetic risk status. Current consensus is that breaching a patient's confidentiality to inform relatives of a heritable genetic mutation which places them at increased risk would not meet the threshold for disclosing under the 'serious' and 'imminent' threat test.[125] Situations in which disclosure of the minor's genetic information would prevent serious harm to others may be even rarer, given that testing of minors is generally only conducted in families already known to be at risk.[126] It is an issue common to all family members, and not just minors, and will not be discussed further.

The circumstances in which unauthorised disclosure of the minor's test results might be made should be explained to minors in genetic counselling before testing, so that they know the limits of the confidentiality duty owed to them.

5.4.2 New Zealand Medical Association (NZMA) Code of Ethics

The New Zealand Medical Association (NZMA) Code of Ethics instructs doctors to 'Protect the patient's private information throughout his/her lifetime … unless there are overriding public interest considerations at stake, or a patient's own safety requires a breach of confidentiality'.[127] It also emphasises that patients should be made aware in advance, if possible, where there are limits to the confidentiality which can be provided.[128]

The principles and recommendations within the NZMA Code of Ethics are on all fours with the privacy protection afforded by the Privacy Act 1993 and the HIPC. Indeed, in its recommendations regarding responsibilities to patients, the NZMA Code of Ethics makes explicit reference to the requirement that doctors accept those obligations to patients which are imposed by statutory provisions and the codes of the Privacy Commissioner, among others (Responsibilities to Patients, number 17).

Additionally, the NZMA Code of Ethics does not differentiate between responsibilities to minors and adults in terms of privacy protection: the duty to protect confidentiality applies to all patients, except in those cases where statutory or other regulatory instruments suggest otherwise.

5.4.3 Professional position statements

The need to protect the confidentiality and privacy of competent minors, in particular, barely rates a mention in most of the professional guidelines and position statements on genetic testing of minors that we have examined. However, most profess significant concern for protecting the privacy of minors generally: the need to protect privacy is one of the main reasons given in favour of deferring genetic testing until the individual can make a personal decision. It is likely, therefore, that the relevant professional groups would also be in favour of protecting the confidentiality of competent minors.

The HGSA Policy on Predictive Testing in Children and Adolescents recommends that test results should only be made available to the minor and to those for whom appropriate permission has been granted.[129]

Wertz et al. also endorse the position that if a minor has requested a genetic test, he or she should receive the results and is entitled to keep these confidential even from his or her parents. However, they note that 'In the reality of family living, this will often be impossible'.[130] They further argue that if the genetic information gleaned from the test result would benefit other family members then the minor has a moral responsibility to disclose the test results to concerned family members:[131] this is no more than any moral obligation attaching to any adult in the same situation. No such legal obligation exists.

5.5 Third party access to minors' genetic information

It is important that minors are aware before undergoing testing that they may be denied health insurance on the basis of their test results, or be subject to higher premiums than they might have been otherwise. Insurance may be an issue that many minors, given their age and circumstances, have not had to previously consider.

The issues surrounding disclosure to third parties are the same as those for anyone: they are not all necessarily unique to genetic testing and they are not necessarily unique to competent minors (unlike the privacy concerns of children too young to give their own informed consent to genetic testing).[132] These issues will therefore not be examined further in this report; suffice to say that competent minors enjoy the same confidentiality privileges and privacy as adults.

6 COMMENTS

Competent minors who have had genetic testing on the basis of their own informed consent are entitled to the same rigorous protection of their privacy and confidentiality as adults. This is particularly important in the genetic testing context because of the greater family interest in learning the information, and the current lack of any legal duty on parents or others who learn of the results to keep such information private.

ENDNOTES

1 Heather Skirton 'Telling the children,' pp 103-11, 107, in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998. Quote from a woman married to man currently affected by HD, with three daughters between the ages of 18 and 26 years.

2 Kolata, Gina (1994) 'Should Children Be Told if Genes Predict Illness' *The New York Times* (online edition), September 26, 1994, referring to Dr. Barbara Weber, University of Pennsylvania School of Medicine.

3 This point is adapted slightly from one made in Allyn McConkie-Rosell and Gail A. Spiridigliozzi 'Family Matters: A Conceptual Framework for Genetic Testing in Children' in *Journal of Genetic Counseling*, Vol. 13, No. 1, February 2004, 9-29, 10. There is also an argument that people have a right 'not to know' that they are at risk for a heritable genetic disorder. However, this argument is usually applied in respect of having a right not to know whether one is affected by a mutation or not (a right not be tested), rather than a right to not know whether one is at risk, particularly where there are prophylactic or beneficial treatments available. The focus of this section is on competent minors who want to give their own informed consent to genetic testing, rather than those who do not want to know their risk status, and thus the right 'not to know' will not be discussed further here (although it is discussed further in the section on children too young to give their own informed consent). For an interesting discussion on whether the right not to know can be justified in the name of autonomy see Phillipa Malpas (2005) 'The right to remain in ignorance about genetic information – can such a right be defended in the name of autonomy' *Journal of the New Zealand Medical Association*, 118, 1220.

4 For a recent general and comprehensive outline of general principles of health information, privacy and disclosure, and related common law principles see John Dawson 'Health Information Law: General Principles' pp 257-268, 'Privacy and Disclosure of Health Information' pp 269-324 and 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

5 There are a number of other rules, regulations, statutory provisions and common law principles which allow disclosure of health information, but these are the most relevant rules for our purposes. See John Dawson 'Health Information Law: General Principles' pp 257-268, 'Privacy and Disclosure of Health Information' pp 269-324 and 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

6 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 302 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

7 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 302 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

8 B.S. Elger and T.W. Harding (2006) 'Should children and adolescents be tested for Huntington's disease? Attitudes of future lawyers and physicians in Switzerland' *Bioethics* Jun 2006; 20(3): 158-167, 165, referring to L.J. Deftos, 'The Evolving Duty to Disclose the Presence of Genetic Disease to Relatives' *Academic Medicine* (1998) 73 962-968.

9 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 331 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
10 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 337-338 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006. See pp 334-339 regarding the difficulty of establishing a 'duty to warn' in cases involving threats or a risk of violence to others from a patient the health professional is treating.
11 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 292 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, referring to *Case No. 194, 202 and 226*, 6 CCNO 111.
12 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 292 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
13 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 293 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
14 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 294 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
15 See *R v Laufau and Laufau* (High Court, Auckland, 23/8/00 and 2/10/00, T.000759).
16 The Court of Appeal, in *R v Lunt* (2003) 20 CRNZ 681, Blanchard, Goddard, William Young JJ, 31 October 2003, Court of Appeal (CA391/03, CA392/03) interpreted the expression 'necessaries of life' to encompass 'goods and services (food, clothing, housing, medical care) necessary to sustain life … albeit in relation to goods and services it is a flexible expression capable of adjusting to changing times and circumstances' (per Blanchard J, para [23].) The case of *R v Lunt* involved the failure of caregivers to protect a small child from violence (from which she died). The Court noted that it would be a 'distortion of plain words' to describe the parental function of protecting a child from harm as a necessary of life. If the Court does not accept that protecting a small child from violence is a parental failure to provide the necessaries of life, it is unlikely to accept that failure to inform a minor about increased risk for a heritable genetic mutation falls within the provision.
17 *R v Lunt* (2003) 20 CRNZ 681, Blanchard, Goddard, William Young JJ, 31 October 2003, Court of Appeal (CA391/03, CA392/03), per Blanchard, J, para [23].
18 Blanchard J reasoned that while s 9 of the Crimes Act 1961 abolishes the New Zealand common law offences, it does not abolish the underlying common law duties. Blanchard J referred to *R v Mwai* [1995] 3 NZLR 149 for authority. *R v Mwai,* discussed in greater detail in the text above, concerned a man charged with criminal nuisance for failing to disclose his HIV-positive status to women he had unprotected sex with. Hardie Boys J noted that the statutory duty, in s 156 of the Crimes Act 1961, to take reasonable precautions, when in charge of dangerous things, to avoid endangering human life, 'is really no more than a particular aspect of the more general common law duty not to engage in conduct which one can foresee may expose others to harm.' (p 281) His Honour contended that 'if the statutory duty does not apply, the general duty at common law plainly does. Ample precedent is to be found in cases decided long before the HIV virus emerged.' (p 282).
19 *R v Lunt* (2003) 20 CRNZ 681, Blanchard, Goddard, William Young JJ, 31 October 2003, Court of Appeal (CA391/03, CA392/03), per Blanchard J, para [27], citing *Adams on Criminal Law*, Wellington, Brookers, 1992, at CA160.14 (referring to the phrase 'any legal duty' in s 160(2)(b) relating to culpable homicide).
20 [1995] 3 NZLR 149; (1995) 13 CRNZ 273 (CA).
21 p 282.
22 (1995) 13 CRNZ, Cooke, P, Hardie Boys, Tompkins, JJ.
23 (1995) 13 CRNZ, Cooke, P, Hardie Boys, Tompkins, JJ, per Tompkins, J, p 149.
24 (1995) 13 CRNZ, Cooke, P, Hardie Boys, Tompkins, JJ.
25 (1995) 13 CRNZ, Cooke, P, Hardie Boys, Tompkins, JJ, per Tompkins, J, p 151.
26 [1995] 3 NZLR 149; (1995) 13 CRNZ 273 (CA), p 281.

27 *Police v Dalley* (2005) 22 CRNZ 495, Judge S E Thomas, 4 October 2005, District Court, Wellington (CRI-2004-085-009168)).
28 para 47.
29 para 49.
30 para 35.
31 If information that a person was at risk for a heritable disorder was a 'dangerous thing,' giving rise to a duty of care, health professionals also could conceivably be obliged to disclose the information to at risk individuals. Is a health professional 'in charge of' the health information? The Court of Appeal noted in *R v Turner* (1995) 13 CRNZ, Cooke, P, Hardie Boys, Tompkins, JJ, per Tompkins, J that 'The High Court was correct to hold that it was not essential for the Crown to prove that an accused had sole, complete, or exclusive charge or control over a thing to succeed with a charge under s 156 Crimes Act 1961.' Notwithstanding, it is highly unlikely that health professionals would be liable for breaching the duty of care in respect of omitting to inform a minor of her increased risk status due to a parent's genetic status, because of the 'lawful excuse' proviso in s 156.
32 *Adams on Criminal Law* CA157.01, accessed from www.brookersonline.co.nz, on 30/10/06.
33 *Adams on Criminal Law* CA157.01, accessed from www.brookersonline.co.nz, on 30/10/06.
34 To establish culpable homicide by omission of a legal duty (s 160(2)(b) Crimes Act) the prosecution must establish, among other elements: that death would not have occurred as and where it did but for the omission; that the death can be attributed to the person's conduct even if the person's conduct was not the sole cause of death; that at the time of the death the omission was an 'operating and substantial cause' of death; and that there was no lawful excuse for omitting to perform the legal duty. *Adams on Criminal Law* notes that there may be cases where death would not have occurred as and when it did but for the person's conduct or omission, but the cause is nonetheless too remote or insubstantial. Additionally, pursuant to s 162 of the Crimes Act, 'No one is criminally responsible for the killing of another unless the death takes place within a year and a day after the cause of death.' There are thus many (probably insurmountable) hurdles to jump before a parent could be charged with culpable homicide as result of their child dying of a heritable genetic mutation that her parents had never informed her that she was at risk for (not least of which is establishing that the parents even had a legal duty to inform the child).
35 Kenneth P. Tercyak, Randi Streisand, Beth N. Peshkin and Caryn Lerman (2000) 'Psychosocial Impact of Predictive Testing for Illness on Children and Families: Challenges for a New Millennium' *Journal of Clinical Psychology in Medical Settings* Volume 7, Number 1, March, 2000, 55-68, 60.
36 S. Whitelaw, J.M. Northover, and S.V. Hodgson (1996) 'Attitudes to predictive DNA testing in familial adenomatous polyposis' *J Med Genet* 33; 540-543, 541.
37 S. Whitelaw, J.M. Northover, and S.V. Hodgson (1996) 'Attitudes to predictive DNA testing in familial adenomatous polyposis' *J Med Genet* 33; 540-543, 541.
38 S. Whitelaw, J.M. Northover, and S.V. Hodgson (1996) 'Attitudes to predictive DNA testing in familial adenomatous polyposis' *J Med Genet* 33; 540-543, 542.
39 Ami Rosen, Sylvan Wallenstein, Margaret M. McGovern (2002) 'Attitudes of Pediatric Residents Toward Ethical Issues Associated With Genetic Testing in Children' *Paediatrics* 110, 2, 360-363.
40 B.S. Elger and T.W. Harding (2006) 'Should children and adolescents be tested for Huntington's disease? Attitudes of future lawyers and physicians in Switzerland' *Bioethics* Jun 2006; 20(3): 158-167, 162.
41 B.S. Elger and T.W. Harding (2006) 'Should children and adolescents be tested for Huntington's disease? Attitudes of future lawyers and physicians in Switzerland' *Bioethics* Jun 2006; 20(3): 158-167, 163.
42 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502.

43 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 495.
44 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 496.
45 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 495-496.
46 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 495-496.
47 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 497.
48 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 497-498.
49 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 499.
50 N. Hallowell, A. Ardern-Jones, R. Eeles, C. Foster, A. Lucassen, C. Moynihan, and M. Watson (2005) 'Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities an problems' *Clin Genet* 67: 492-502, 501.
51 Heather Skirton 'Telling the children,' pp 103-11, in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
52 Heather Skirton 'Telling the children,' pp 103-11, 105 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
53 Heather Skirton 'Telling the children,' pp 103-11, 105 in Clarke, Angus (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
54 Heather Skirton 'Telling the children,' pp 103-11, 107 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
55 Heather Skirton 'Telling the children,' pp 103-11, 107 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
56 Heather Skirton 'Telling the children,' pp 103-11, 108 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
57 Heather Skirton 'Telling the children,' pp 103-11, 108 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
58 Kenneth P. Tercyak, Randi Streisand, Beth N Peshkin, and Caryn Lerman (2000) 'Psychosocial Impact of Predictive Testing for Illness in Children and Families: Challenges for a New Millennium' Journal of Clinical Psychology in Medical Settings Vol. 7, No. 1, 55-68, p 58-59.
59 Kenneth P. Tercyak, Randi Streisand, Beth N. Peshkin and Caryn Lerman (2000) 'Psychosocial Impact of Predictive Testing for Illness on Children and Families: Challenges for a New Millennium' *Journal of Clinical Psychology in Medical Settings* Volume 7, Number 1, March, 2000, 55-68, 59-60.
60 Kenneth P. Tercyak, Randi Streisand, Beth N. Peshkin and Caryn Lerman (2000) 'Psychosocial Impact of Predictive Testing for Illness on Children and Families: Challenges for a New Millennium' *Journal of Clinical Psychology in Medical Settings* Volume 7, Number 1, March, 2000, 55-68, 60. The benefit of giving children the ability to make informed choices and plan their lives, taking the risk of the disease into account, was also cited as a benefit of disclosure by the parents in Skirton's study (Heather Skirton 'Telling the children,' pp 103-11, 108-109 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998).

61 Heather Skirton 'Telling the children,' pp 103-11, 109 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
62 Heather Skirton 'Telling the children,' pp 103-11, 109 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.
63 Phillipa J Malpas (2006) 'Telling at risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?' *Upcoming Current Controversies in JME*, accessed from http://jme.bmjjournals.com/preprint/ecurrent.dtl.
64 For this point Malpas (Phillipa J Malpas (2006) 'Telling at risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?' *Upcoming Current Controversies in JME*, accessed from http://jme.bmjjournals.com/preprint/ecurrent.dtl) cites research indicating that individuals who learnt about their HD risk status during adolescence rather than during adulthood 'suffered severely from the burden of HD' and were 'significantly more pessimistic about their future.' I.M. Van der Steenstraten, A. Tibben, R.A.C. Roos et al. (1994) 'Predictive testing for Huntington disease: Nonparticipants compared with participants in the Dutch program.' *Am J Hum Genet* Oct 55(4): 618-625.
65 Phillipa J. Malpas (2006) 'Telling at risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?' *Upcoming Current Controversies in JME*, p 6, accessed from http://jme.bmjjournals.com/preprint/ecurrent.dtl, citing Ellen Wright Clayton (1997) 'Genetic testing in children' *J Med Philosophy* 22:233-251, p 246.
66 Phillipa J. Malpas (2006) 'Telling at risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?' *Upcoming Current Controversies in JME*, p7, accessed from http://jme.bmjjournals.com/preprint/ecurrent.dtl.
67 Malpas then proceeds to argue that these points also favour predictive testing of children. That issue is discussed in greater depth in the section above on minors who cannot give their own informed consent to testing.
68 Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998, pp 9-10.
69 M. Cappelli, S. Verma, Y. Korneluk, A. Hunter, E.V. Tomiak, J. Allanson, C. DeGrasse, L. Corsini and L. Humphreys (2005) 'Psychological and genetic counseling implications for adolescent daughters of mothers with breast cancer' *Clin Genet* 67: 481-491, 490.
70 American Society of Human Genetics/American College of Medical Genetics Report, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents,* 1995, accessed from www.ashg.org/genetics/ashg/pubs/policy/pol-13.htm on 8 May 2006.
71 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 337-338 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
72 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 337-338 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
73 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 294 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
74 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 294 in P.D.G. Skegg andR. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
75 See *R v Laufau and Laufau* (High Court, Auckland, 23/8/00 and 2/10/00, T.000759).
76 *R v Lunt* (2003) 20 CRNZ 681, Blanchard, Goddard, William Young JJ, 31 October 2003, Court of Appeal (CA391/03, CA392/03), per Blanchard, J, para [23], citing *Russell on Crime* (12th ed) London, Stevens & Sons, 1964, pp 402-3.
77 If information that a person was at risk for a heritable disorder was a 'dangerous thing,' giving rise to a duty of care, health professionals also could conceivably be obliged to disclose the information to at risk individuals. Is a health professional 'in charge of' the health information? The Court of

Appeal noted in *R v Turner* (1995) 13 CRNZ, Cooke, P, Hardie Boys, Tompkins, JJ, per Tompkins, J, that 'The High Court was correct to hold that it was not essential for the Crown to prove that an accused had sole, complete, or exclusive charge or control over a thing to succeed with a charge under s 156 Crimes Act 1961.' Notwithstanding, it is highly unlikely that health professionals would be liable for breaching the duty of care in respect of omitting to inform a minor of her increased risk status due to a parent's genetic status, because of the 'lawful excuse' proviso in s 156. Health professionals could rely upon the lawful excuse of protecting confidentiality.

78 Informing a child of a negative test result must still be managed in a sensitive way, particularly depending on the family circumstances. It has been documented that some children feel 'survivor guilt' when a parent or sibling is affected by a condition, and the child herself is not.

79 Michie, Susan and Marteau, Theresa M. ((1996) 'Predictive genetic testing in children: The need for psychological research' *British Journal of Health Psychology* 1, 3-14, 6, referring to L.A. Slavin,M.D. O'Malley, G.P. Koocher, and D.J. Foster (1982) 'Communication of the cancer diagnosis to pediatric patients; Impact on long-term adjustment' *American Journal of Psychiatry*, 139, 179-183.

80 Dorothy C. Wertz 'International Perspectives,' pp 271-287, 277 in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers, Oxford, 1998.

81 Dorothy C. Wertz 'International Perspectives,' pp 271-287, 279-280 in Angus Clarke (Ed.) *The Genetic Testing of Children* BIOS Scientific Publishers, Oxford, 1998.

82 A.F. Patenaude, L. Basili, D.L. Fairclough and F.P. Li (1996) 'Attitudes of 47 mothers of pediatric oncology patients toward genetic testing for cancer predisposition' *Journal of Clinical Oncology*, Vol 14, 415-421, 418.

83 R.E. Duncan, J. Savulescu, L. Gillam, R. Williamson, and M.B. Delatycki (2005) 'An international survey of predictive genetic testing in children for adult onset conditions' *Genet Med.* 2005 Jul-Aug;7(6):390-6, 393.

84 R.E. Duncan, J. Savulescu, L. Gillam, R. Williamson, and M.B. Delatycki (2005) 'An international survey of predictive genetic testing in children for adult onset conditions' *Genet Med.* 2005 Jul-Aug;7(6):390-6, 393.

85 Anita Jolly, Evelyn Parsons and Angus Clarke 'Identifying carriers of balanced chromosomal translocations: interviews with family members,' pp 61-90, p 82, Angus Clarke *The Genetic Testing of Children* BIOS Scientific Publishers Ltd, Oxford, 1998.

86 Human Genetics Society of Australasia (2005) *Predictive Testing in Children and Adolescents*, Version 2, April 2005, pp 2-3. Accessed on 8 May 2006 from http://hgsa.com.au/images/UserFiles/Attachments/Predictivetesting(General)APRIL2005.pdf.

87 Human Genetics Society of Australasia (2005) HGSA Policy, *Presymptomatic and Predictive Testing for Genetic Disorders,* Version 2, April 2005, accessed 30 January 2007 from http://hgsa.com.au/images/UserFiles/Attachments/PresymptomaticandPredictiveTestingforGeneticDisordersV22005.pdf.

88 Phillipa J. Malpas (2006) 'Telling at risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?' *Upcoming Current Controversies in JME*, p5, accessed from http://jme.bmjjournals.com/preprint/ecurrent.dtl.

89 Phillipa J. Malpas (2006) 'Telling at risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?' *Upcoming Current Controversies in JME*, pp 11-12, accessed from http://jme.bmjjournals.com/preprint/ecurrent.dtl.

90 Kenneth P. Tercyak, Randi Streisand, Beth N. Peshkin and Caryn Lerman (2000) 'Psychosocial Impact of Predictive Testing for Illness on Children and Families: Challenges for a New Millennium' *Journal of Clinical Psychology in Medical Settings* Volume 7, Number 1, March, 2000, 55-68, 63.

91 Heather Skirton 'Telling the children,' pp 103-11, 110 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.

92 Heather Skirton 'Telling the children,' pp 103-11, 110 in Angus Clarke (Ed.) *The Genetic Testing of Children*, BIOS Scientific Publishers Ltd, Oxford, 1998.

93 Pascal Borry, Jean-Pierre Fryns, Paul Schotsmans, and Kris Dierickx (2006) 'Carrier testing in minors: a systematic review of guidelines and position papers' *European Journal of Human Genetics* 14, 133-138, 137.
94 See the Human Genome Research Project's report on 'Choosing Genes for Future Children' for further discussion on the regulatory framework surrounding PGD.
95 G.K. Suthers, J. Armstrong, J. McCormack, D. Trott (2006) 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder; *J Med Genet* 43: 665-670.
96 G.K. Suthers, J. Armstrong, J. McCormack, D. Trott (2006) 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder; *J Med Genet* 43: 665-670, 666.
97 G.K. Suthers, J. Armstrong, J. McCormack, D. Trott (2006) 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder; *J Med Genet* 43: 665-670, 670 (Appendix).
98 World Health Organisation Human Genetics Programme (2003) *Review of Ethical Issues in Medical Genetics* Geneva, p 60, accessed on 15 February 2007 from www.who.int/genomics/publications/en/ethical_issuesin_medgenetics%20report.pdf.
99 Clinical Genetics Society (UK) (1994) 'The Genetic Testing of Children, Report of a Working Party of the Clinical Genetics Society, Chaired by Dr Angus Clarke' J *Med Genet* 1994; 31; 785-797, 794.
100 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 58, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)
101 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 62, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)
102 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 61, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)
103 John Dawson 'Privacy and Disclosure of Health Information' pp 269-324, 311 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.
104 Good grounds for withholding the information if the request has been made by the individual concerned have been discussed above in the context of disclosure of genetic risk and genetic test results to the minor. An agency may refuse to disclose any information requested if: disclosure would involve the unwarranted disclosure of the affairs of another individual (s 29(1)(a) Privacy Act 1993); disclosure of the information would be likely to prejudice the physical or mental health of that individual (s 29(1)(c)); or in the case of an individual under the age of 16, the disclosure of that information would be contrary to that individual's interests (s 29(1)(d)). Similar concerns as those raised by rule 11(4)(b)(i) f the HIPC arise when considering whether to refuse disclosure to parents pursuant to section 22F(2) of the Health Act 1956 and sections 29(1)(c) or 29(1)(d) of the Privacy Act 1993.
105 The privacy and confidentiality duties owed to competent minors is discussed further below under the heading 'Competent Minors and Privacy'.
106 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 66, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)
107 S. Johnson, N.E. Kass, and M. Natowicz 'Disclosure of Personal Medical Information: Differences among Parents and Affected Adults for Genetic and Nongenetic Conditions', *Genetic Testing*, Volume 9, Number 3, 2005, 269-280, 279.
108 S.A.M. McLean (1995) 'Genetic Screening 0f Children: The UK Position', *The Journal of Contemporary Health Law and Policy*, Volume 12:113-130, 117.

109 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 327 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, referring to the established elements of the breach of confidence action as listed by Megarry J in *Coco v A N Clark (Engineers) Ltd* [1969] RPC 41.

110 See *Attorney-General v Guardian Newspapers Ltd (No 2)* [1990] 1 AC 109, 281, per Lord Goff: 'a duty of confidence arises when confidential information comes to the knowledge of a person … in circumstances where he has notice, or is held to have agreed, that the information is confidential, with the effect that it would be just in all the circumstances that he should be precluded from disclosing the information to others.' Also 'This statement of principle, which omits the requirement of a prior confidential relationship, was accepted as representing current English law by the European Court of Human Rights in *Earl Spencer v United Kingdom* (1998) 25 EHRR CD 105 and was applied by the Court of Appeal in *A v B plc* [2003] QB 195, 207. It is now firmly established.' *Campbell v. MGN Limited* [2004] UKHL 22, per Lord Hoffman, at 48.

111 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, refers to *A-G v Guardian Newspapers Ltd (No 2)* [1990] 1 AC 109 (HL).

112 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 328, in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

113 For example, issues relating to: parental interests in disclosing their child's genetic test results to certain people or agencies and their right to freedom of expression (s 14 New Zealand Bill or Rights Act 1990); the need for identifiable harm to have been suffered in order for a remedy to be granted; and what defences may be available to parents who breached such a duty e.g. consent to disclosure or waiver of confidentiality; statutory authority for disclosure; or a public interest defence. See John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 330-332, in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.).

114 *Hosking v Runting* [2005] 1 NZLR 1; (2004) 7 HRNZ 301 (CA).

115 *Hosking v Runting* [2005] 1 NZLR 1, per Tipping J, para 259.

116 *Hosking v Runting* [2005] 1 NZLR 1, paras 145 and 147.

117 John Dawson 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339, 334, in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006.

118 For an interesting example of how one Clinical Genetics Service in South Australia informed family members of their genetic risk status see G.K. Suthers, J. Armstong, J. McCormack and D. Trott (2006) 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder' *J Med Genet* 43: 665-670, accessed 4 August 2006 from http://jmg.bmjjournals.com/cgi/rapidpdf/jmg.2005.039172v1.

119 Vic Larcher (2005) 'Consent, competence and confidentiality' *BMJ* 330, 353-356, 354.

120 Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, p 26 (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)

121 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 64, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)

122 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 65, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)

123 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 65, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)

124 Sarah Kerkin 'Disclosing children's health information: A legal and ethical framework,' p 65, in Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)

125 For example, see Human Genetics Society of Australasia (2005) HGSA Policy, *Presymptomatic and Predictive Testing for Genetic Disorders,* Version 2, April 2005, p 4, accessed 30 January 2007 from http://hgsa.com.au/images/UserFiles/Attachments/PresymptomaticandPredictiveTestingforGeneticDisordersV22005.pdf.

126 D.C. Wertz, J.H. Fanos and P.R. Reilly (1994) 'Genetic testing for children and adolescents. Who decides?' *JAMA*. Sep 21;272(11):875-81, 878.

127 New Zealand Medical Association Code of Ethics, Principles of Ethical Behaviour, Number 5, accessed on 6 April 2007 from http://www.nzma.org.nz/about/ethics/codeofethics.pdf.

128 New Zealand Medical Association Code of Ethics, Principles of Ethical Behaviour, Number 14, accessed on 6 April 2007 from http://www.nzma.org.nz/about/ethics/codeofethics.pdf.

129 Human Genetics Society of Australasia Policy *Predictive Testing in Children and Adolescents*, Version 2, April 2005, p 4. Accessed on 8 May 2006 from http://hgsa.com.au/images/UserFiles/Attachments/Predictivetesting(General)APRIL2005.pdf.

130 D.C. Wertz, J.H. Fanos and P.R. Reilly (1994) 'Genetic testing for children and adolescents. Who decides?' *JAMA*. Sep 21;272(11):875-81, 878.

131 D.C. Wertz, J.H. Fanos and P.R. Reilly (1994) 'Genetic testing for children and adolescents. Who decides?' *JAMA*. Sep 21;272(11):875-81, 878.

132 For further information about third party access to health information generally see John Dawson 'Health Information Law: General Principles' pp 257-268, 'Privacy and Disclosure of Health Information' pp 269-324 and 'Common Law Principles Concerning Confidentiality, Privacy and Disclosure' pp 325-339 in P.D.G. Skegg and R. Paterson (Eds.) *Medical Law in New Zealand* Brookers Ltd, Wellington, 2006, and the website of the Office of the Privacy Commissioner, at www.privacy.org.nz.