Keeping Mum:
Should doctors be able to breach confidentiality to inform patients' relatives of genetic risks?

Elizabeth Hadlow

A dissertation submitted in partial fulfilment of the requirements of the degree of Bachelor of Laws (Honours) at the University of Otago – Te Whare Wananga o Otago

October 2019

Acknowledgments

To my supervisor Colin Gavaghan, thank you for your guidance, insight, and discussion. Without your enthusiastic support, this dissertation could not have got off the ground.

To Barry Allan, Stephen Robertson and Jeanne Snelling for your expertise and time.

To my amazing friends, I genuinely cannot thank you all enough for the years of support and fun.
Especially to Clara Sinclair, for editing, advice and motivation.

And finally, to my family, for your support, insight, and general interest in this dissertation.
Particularly to Dad, who patiently edited my work throughout the year.

Thank you all.

TABLE OF CONTENTS

Introduction

The human genome project started in 1990 and was declared complete in 2003, with over 98% of the gene-containing part of the human genome sequenced.[1] This, coupled with Next Generation Sequencing technologies that became widely available in the early 21st century, has led to an upsurge of human genome sequencing in medicine. Using this current technology, a person's entire genome can be sequenced cheaply and within a day;[2] hence, information derived from genetic testing is being increasingly utilised in general medicine.[3] On top of this, popular direct-to-consumer genetic testing companies such as EasyDNA and 23andMe offer DNA results for ancestry, paternity, and health conditions. Consequently, there is a wave of genetic information coming into the mainstream, and inevitably into a doctor's office.

Genetic causation factors are now recognised to play an important role in disease beyond the classic genetic disorders like Huntington's disease, cystic fibrosis, and Duchenne muscular dystrophy. Scientists have discovered that genetics can play strong roles in more complex diseases, such as cancers and psychiatric illnesses.[4] With increased genetic testing of patients, more information is being discovered that not only relates to the patient, but to their genetic relatives as well. This can create issues around medical confidentiality for doctors who have contact with both the patients and their families. For a multitude of various reasons, patients occasionally do not wish to have their families notified about their genetically-linked conditions. If a patient refuses to give consent for their doctor to notify relatives of potential genetic risks, then the doctor is in a conundrum: can they break doctor-patient confidentiality and disclose the information to their patient's relatives? And even if they could, in what situations should they?

For example: John and his wife Linda have a child who has been diagnosed with cystic fibrosis, a recessive disease that requires the child to inherit a defect gene from each parent. John has a brother David that he does not talk to as they had a falling out some years earlier. However,

---

[1] Francis S. Collins, Michael Morgan & Aristides Patrinos "The Human Genome Project: Lessons from Large-Scale Biology" (2003) 300 Science 286 at 287

[2] It was USD$95,263,072 to sequence a genome in 2001, now in 2019 it is USD$1,301

[3] Sam Behjati & Patrick S Tarpey "What is next generation sequencing?" (2013) 98 Arch Dis Child Educ Pract Ed 236 at 236

[4] The Wellcome Trust Case Control Consortium "Genome-wide association study of 14,000 cases of seven common diseases and 3,000 shared controls" (2007) 447 Nature 661

they both go to the same general practitioner (GP) who knows that John's child has cystic fibrosis. John refuses to allow the GP to tell David of his risk of carrying the defective gene, which could affect his future reproductive decisions. Should the GP have the ability to break confidentiality and tell David of his genetic risk?

This topic is complex and encounters several philosophical and practical elements that tend to conflict. This dissertation endeavours to unpick some of these factors in law and philosophy to find a path forward that provides medical professionals some ability to disclose information to genetic relatives where appropriate. Chapter One explores the background of this issue. Chapter Two will look at the case that kick-started a resurgence of thought in this arena, the English Court of Appeal's recent decision in *ABC v St George's Healthcare NHS Trust and others* [2017],[5] and will review the legal position in New Zealand, United States and Australia. Chapter Three will delve into the underpinnings of the law, and the arguments for and against the imposition of a legal duty or a discretion to contact relatives. Chapter Four will build on the previous chapters to create a possible model legal framework for practitioners to follow.

[5] *ABC v St George's Healthcare NHS Trust and others* [2017] EWCA Civ 336

I. The Background Context

A. Genetic exceptionalism

Medicine is built upon the foundations of privacy, confidentiality, and autonomy of the patient. Under these principles, a patient has the right to control information relating to themselves and who may access that information. Thus, if a patient chooses not to allow their doctor to inform relatives, then that is the patient's right.[6] While this structure works well for the majority of medicine, difficulties can arise with genetic information. Unlike classic medical information, genetic information is, by its nature, familial. It not only relates to the patient, but also their parents, siblings and any biological relative, due to the inheritance of genes. Relatives can therefore have an interest in knowing genetic information that has been obtained from the patient.[7]

How genetic information should be perceived and managed is subject to academic debate. Some argue that it should be no different from other types of medical information, whereas others see it as "exceptional",[8] due to its predictive qualities and familial nature.[9] The position of treating genetic information differently has been adopted in many different approaches to medical privacy. Feminists, and the proponents of ethics of care, argue that family relationships produce a moral responsibility to share information.[10] Similarly, communitarian theory posits that a patient who possesses information that impacts on others, is under a moral responsibility to share that information.[11] These arguments take the stand that due to the familial nature of genetics, a patient has no exclusive right to control access to the information.[12]

This dissertation takes the approach that in regard to medical privacy, genetic information is not the same as other types of medical information. Its familial nature means that information obtained from genetic testing does not simply concern one individual; therefore, that individual should not have full control over who can access that information. In addition, the predictive

---

[6] Roy Gilbar & Sivia Barnoy "Disclosure of genetic information to relatives in Israel: between privacy and familial responsibility" (2012) 31(4) New Genet Soc 391 at 391
[7] Dean Bell & Belinda Bennett "Genetic Secrets and the Family" (2001) 9 Med Law Rev 130 at 130
[8] The ideal of "exceptionalism" in medicine originated in 1991 from the HIV epidemic (see Lainie Friedman Ross "Genetic exceptionalism vs paradigm shift: Lessons from HIV" (2001) 21(2) J Law Med & Ethics 141)
[9] Gilbar & Barnoy, at 392
[10] Roy Gilbar "Between unconditional acceptance and responsibility: should family ethics limit the scope of reproductive autonomy?" (2009) 21 Child & Fam L Q 309 at 310
[11] Rosamond Rhodes "Genetic links, family ties and social bonds: rights and responsibilities in the face of genetic knowledge" (1998) 23(1) J Med Philos 10 at 21
[12] Gilbar & Barnoy, at 392

quality of genetics generally allows some certainty that a disease will present phenotypically if the risk alleles are carried. Therefore, knowledge of these risks is important for anyone potentially carrying these genes.

B. Reasons why patients do not want relatives informed

This topic is only an issue when the patient refuses to consent to their doctor informing relatives of genetic risks. It seems counter-intuitive to wish to have this information withheld from family who would seemingly benefit from this knowledge. But there are a multitude of reasons why patients do not want their families informed. These include cognitive changes; the notion that they will shield others from distress; the breakdown of familial relationships; denial of the condition; uncertainty around how to share the information; thinking that relatives are too unwell or busy to hear the news; believing it is not relevant for relatives to know; fear of discrimination or stigmatisation; not understanding or acknowledging others could be at risk; believing the relatives would prefer not to know; financial implications; fear of non-paternity or non-maternity; and cultural, religious and spiritual views.[13] Hence, doctors may find themselves in a situation where their patient has forbidden them from disclosing information to the patient's family.

C. A paradigm situation

There is a wide scope of situations where this issue may arise, therefore this dissertation will be primarily restricted to a paradigm situation. The scenario consists of a professional relationship between the general practitioner (GP) and the patient, as well as an independent professional relationship with the patient's relatives. Therefore, the GP has a duty of care to all parties involved. Research has found that GPs play an important role as "gatekeepers" to genetic information as they will often order genetic testing.[14] Due to this role it is likely that GPs will be faced with a situation where they may want to breach confidentiality. In addition, GPs would have the contact details of the relatives and the ability to inform them if any relevant information arises. While the cases discussed in this dissertation seldom strictly adhere to this paradigm,

[13] National Health and Medical Research Council "Use and disclosure of genetic information to a patient's genetic relatives under Section 95AA of the Privacy Act 1988 (Cth)" (2014) PR3 at 29; Angus Clarke, Martin Richards, Lauren Kerzin-Storrar, Jane Halliday, Mary Anne Young, Sheila A Simpson, Katie Featherstone, Karen Forrest, Anneke Lucassen, Patrick J Morrison, Oliver W J Quarrell, Helen Stewart & collaborators "Genetic professionals' reports of nondisclosure of genetic risk information within families" (2005) 13 Eur J Hum Genet 556 at 559

[14] Sonya Morgan, Deborah McLeod, Alexa Kidd & Barbara Langford "Genetic testing in New Zealand: the role of the general practitioner" (2004) 117(1206) N Z Med J 1 at 1

they contain the common element of a proximate relationship between the discloser and recipient of the information, so these cases are useful when analysing this area of law.

D. Conclusion

With the amount genetic information available and its familial nature, it needs to be regarded as distinct from other types of medical information when it comes to privacy. It does not fit into the individual information model that medicine has created and this gap needs to be accounted for. It is also important to recognise the validity of the reasons why patients do not want their relatives being notified about genetic risks, as this is where the whole issue stems from.

II. The Current Law

This chapter will summarise the landmark case that started a resurgence of thought in this area of law. It will then explore options for disclosure in New Zealand, and lastly, review the developments in the United States and Australia.

A. A landmark case: *ABC v St George's Healthcare NHS Trust and Others* [2017]

This issue of breaching confidentiality has come before the courts in England, in the case of *ABC v St George's Healthcare NHS Trust and Others*.[15] The Court of Appeal's decision reverses the previous strike-out of the case by Nichols J in the High Court. The Court held that the Claimant had an arguable case that the Defendants owed her a duty of care to disclose the genetic diagnosis of her father.[16]

1. The facts

The Claimant alleged that the first Defendant, St George's NHS Trust, owed her a duty of care under the tort of negligence. In 2007, the Claimant's father shot and killed her mother. After conviction on the ground of diminished responsibility, he was referred to St George's Hospital, and in 2009 it was confirmed that he was suffering from Huntington's disease.[17] Huntington's disease is a terminal, late onset, progressive neurodegenerative disorder, with no treatments available to slow or stop the progression of the disease. It has autosomal dominant inheritance, so the Claimant has a 50% chance of inheriting the disease allele, and therefore a 50% chance of developing the disease. Symptoms include physical chorea, impaired cognition and psychiatric disorders.[18] When the father's diagnosis was confirmed, he refused to disclose this information to the Claimant. He also refused to allow his therapists to inform her of his diagnosis.[19]

In 2009, the Defendants organised group therapy sessions between the Claimant and her father.[20] Subsequently in late 2009, the Claimant informed her father that she was pregnant,[21]

---

[15] *ABC*, above n 5
[16] Note, as a strike-out appeal, the decision was not a judgment of the merits of the case
[17] *ABC*, at [10]
[18] The Huntington's Disease Collaborative Research Group "A novel gene containing trinucleotide repeat that is expanded and unstable on Huntington's disease chromosomes" (1993) 72 Cell 971 at 971
[19] *ABC*, at [7]
[20] *ABC*, at [16]
[21] At [8]

and he continued to refuse to tell her his diagnosis until after she had her baby, as he felt that she "might get upset, kill [herself], or have an abortion".[22] After the Claimant gave birth, she was accidentally informed about her father's diagnosis by one of his doctors.

2. The claim

The Claimant alleges that the Defendants owed her a duty of care, due to her participation in the family therapy sessions in 2009. She asserts that she attended the therapy in the capacity of "a patient of the Defendants", which established a special relationship that would give grounds for a duty of care.[23] Thus, the Defendants had a responsibility to ensure that the Claimant's psychological and physical well-being was cared for.

The Claimant asserted that in light of her pregnancy, she should have been informed of her father's diagnosis in "in a timely manner when it was known, or ought to have been known, that the Claimant was pregnant".[24] The Claimant asserts that if she had known of the risks, and it was confirmed that she had inherited the gene, she would have terminated the pregnancy.[25]

3. The judgment

The imposition of the duty was decided under the *Caparo* three-fold test for negligence.[26] It was agreed by all that for the purposes of the strike-out appeal, the first two steps of foreseeability and proximity were satisfied. Thus, the judgment focuses only on the third limb: whether it was "fair, just and reasonable" for a duty of care to the Claimant to be imposed on the Defendants, in light of the circumstances.[27]

A critical issue is the consideration of the public interest in disclosing the information.[28] The Defendant argued that in this case there is no public interest that is stronger than that of preserving doctor-patient confidentiality. Confidence in the relationship may be eroded if the patient is aware of a doctor's duty to disclose. However, the Court found that this argument may not be detrimental to the Claimant.[29] On this point, the Claimant argued that it is in the

[22] *ABC*, above n 5, at [11]
[23] At [16]
[24] At [18]
[25] At [15]
[26] *Caparo Industries plc v Dickman* [1990] 2 AC 605 (HL)
[27] *ABC*, at [24]
[28] At [26] & [28]
[29] At [34]

public interest to prevent the conception or birth of a child who may require significant state support due to a parent being affected by Huntington's Disease, and who may grow up to develop the disease themselves.[30] The Court accepted that this position is arguable.

In the consideration of patient autonomy, the Court found that it was inconsistent to value personal decision-making about treatment, while at the same time withhold information relevant to another's health decisions without giving them a legal remedy.[31] Patient autonomy is a key consideration in modern medical law, and according to the Court, it can justify a duty owed to the patient's relatives.[32] Thus, the Court adopted a relational construction of the concept of autonomy and it acknowledged that a decision by one person can have an impact on their relatives.[33]

With regard to the realm of tortious duties, the evolution of the duty of care is preferred so it can keep up with the progression of society.[34] To keep the scope of the duty narrow, the Court differentiated genetic cases from general medicine, using the proximity and foreseeability aspects of *Caparo*.[35] It was noted that since genetic diseases are familial, medical professionals can possess reliable and essential information concerning family members who may be affected. This can lead to that relative to also become a patient.[36]

The Court took into account the General Medical Council's best practice medical guidelines, which acknowledged that confidentiality is not absolute, and that there can be situations where disclosure is acceptable to avoid harm.[37] The three hurdles in this test for disclosure are: the patient refuses to disclose the information, there is a serious harm to an identifiable person, and disclosure of the information may prevent harm from occurring.[38] The benefit conferred to the recipient of the information should be able to justify the breach of confidentiality.[39] The Court recognised that the medical professional must undertake a balancing act between the benefits

[30] *ABC*, above n 5, at [29]
[31] At [28]
[32] Roy Gilbar & Charles Foster "It's arrived! Relational autonomy comes to court: *ABC v St George's Healthcare NHS Trust* [2017] EWCA 336" (2017) 26(1) Med Law Rev 125 at 131
[33] At 132
[34] *ABC*, at [62]
[35] Gilbar & Foster, above n 32, at 132
[36] *ABC*, at [43]
[37] At [19]
[38] Anneke Lucassen & Roy Gilbar "Alerting relatives about heritable risks: the limits of confidentiality" (2018) 361 BMJ 1 at 1
[39] *ABC*, at [19]

of disclosure and the importance of maintaining confidentiality.[40] It was also noted that if the Claimant was more psychologically vulnerable, it may be in the proper course of medical practice to withhold the information, as there is no treatment available for Huntington's disease and the news could be more psychologically damaging than the gain from knowing the diagnosis.[41]

In essence, the case confirms that doctors may have legal duties to disclose genetic information to relatives. If they fail to discharge the duty to disclose, they may attract legal liability. Disgruntled people who were not told, as well as those who have had their confidentiality breached, may both be able to lodge claims against the medical professional. *ABC* is an exciting development in this area of medical privacy law, with the potential to have a wide impact.

B. New Zealand law

ABC presents an opportunity for New Zealand to review its position on non-consensual genetic information disclosure. How New Zealand will approach situations like *ABC* is going to be important for the legal and medical profession alike.

1. Introduction

In New Zealand, the law allows medical professionals to disclose confidential information to another individual with the consent of the patient to whom the information relates.[42] However, without the consent of the patient, the ability of the medical professional to disclose health information becomes limited. Over time, statute and common law have established certain circumstances where disclosure without consent can be permissible.[43] The exceptions to the principle of medical confidentiality are based on the wider circumstances of the situation, the necessity of public interest, and the personal benefits of disclosure.

2. The Heath Information Privacy Code 1994

General non-consensual disclosure is permissible under multiple statutory structures. The most relevant for this issue is the Health Information Privacy Code 1994 (HIPC), which is authorised

[40] *ABC*, above n 5, at [22], [23] & [32]
[41] At [38]
[42] Richman Wee "Disclosure of genetic information to at-risk relatives: privacy law and professional guidance in New Zealand" (2011) 3 JPHC 237 at 238
[43] John Dawson "Privacy and disclosure of health information" in Peter Skegg & Ron Paterson (ed) *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015) 329 at [11.4]

under s 46 of the Privacy Act 1993. However, as the HIPC is a code, the rules within it are not enforceable in a court of law.[44]

a) Rule 11(2)(d): Limits on disclosure of health information

The relevant sections in r 11 is as follows:[45]

> (1) A health agency that holds health information must not disclose the information unless the agency believes, on reasonable grounds:
>
> …
>
> (2) Compliance with paragraph (1)(b) is not necessary if the health agency believes on reasonable grounds that it is either not desirable or not practicable to obtain authorisation from the individual concerned and:
>
> …
>
> (d) that the disclosure of the information is necessary to prevent or lessen a serious […] threat to:
>
> (i) public health or public safety; or
>
> (ii) the life or health of the individual concerned or another individual;
>
> …
>
> (3) Disclosure under subrule (2) is permitted only to the extent necessary for the particular purpose.

Rule 11 gives a discretionary ability, as opposed to a legal duty, on the health agency to disclose without consent.[46] The rationale of this exception is to allow information to be disclosed to avoid a serious detriment to the patient or another person. Thus, the exception is only applicable to the extent that is necessary to fulfill the purpose of disclosure.[47] Case law has confirmed that the rule contains both subjective and objective elements, and the meaning of "necessary" is not as stringent as absolute necessity, rather it is a lower standard of reasonably necessary. [48]

This section has been utilised in circumstances where there is disclosure to protect others from the actions of the individual. Cases that have been heard include situations involving

[44] *Hosking v Runting* [2005] 1 NZLR 1 (CA) at [194] per Keith J
[45] Health Information Privacy Code 1994, r 11
[46] Michael Heron & Amy Jordan "Health professionals and mandatory reporting" (2001) N Z Law J 139 at 139
[47] *Henderson v Privacy Commissioner* [2010] NZHC 554 at [80]
[48] *Cory Alexander Urlich v New Zealand Police* [2019] NZHC 457 at [23]; *Lehmann v Canwest Radioworks Ltd* Decision No 35-06, HRRT 8-04 Sep 21, 2006, Hindle, RDC, Chair at [50]

information relating to the use of drugs, drug-seeking behaviour, and disclosure to the police.[49] This exception has typically been used when there is an external danger to others. It is unclear whether an internal (genetic) danger to another individual without any external threat by the patient would be included.

Disclosure must be to an individual that the discloser reasonably believes is in a position to respond to the information and prevent or lessen the threat and achieve a tangible result in that situation.[50] This requirement could be difficult to pass, as relatives themselves would not be able to achieve results from receiving genetic risk information. Rather, doctors they would consult as a result of the knowledge would be the ones most likely to achieve some tangible result. Whether this situation would satisfy the requirement is unknown.

b) A "serious threat"

Rule 11 calls for a "serious threat" to the individual. "Serious threat" is defined in the Privacy Act for the purposes of r 11:[51]

> **Serious threat**, for the purposes of principle 10(d) or 11(f), means a threat that an agency reasonably believes to be a serious threat having regard to all of the following:
>
> (a) the likelihood of the threat being realised; and
>
> (b) the severity of the consequences if the threat is realised; and
>
> (c) the time at which the threat may be realised

"Serious" is broken down into three elements: probability, severity and time. There is no further guide in the HIPC as to what constitutes a probability that is sufficient to fulfil (a), nor what degree of severity is required for (b). The third element is also troublesome, as often the onset of genetic disease is often unpredictable.

Due to variability between genetic conditions, often it may be impossible to fulfil all three elements of the definition. The likelihood of onset cannot be predicted with all genetic diseases. Some diseases have low penetrance, so that even if the gene is carried the disease will not manifest. In addition, even if it is a disease that is highly penetrant, there is usually only a 50%

[49] E.g. *Henderson v Privacy Commissioner*, above n 47; *Cory Alexander Urlich v New Zealand Police*, above n 48; *Mitchell v Privacy Commissioner* [2017] NZHC 569
[50] *Henderson v Privacy Commissioner*, at [78] and [79]
[51] Privacy Act 1993, s 2

chance or less that the relative will inherit the risk allele, which reduces the likelihood of the threat being realised. As well, the severity of the condition can differ between individual presentations. Affected people in the same family with the same condition can have different levels of severity, and this will not be known at the time the decision to disclose is made.[52] There is also no guarantee of the time of onset with conditions that present later in life, even if there is a high likelihood that the disease will present itself. It is also possible that a disease may never have any phenotypic presentation, even if the risk alleles are carried.

Risk of a relative carrying the disease-causing alleles may be "serious" in some cases, but due to the nature of genetic disease it is not guaranteed to fall under the definition. The definition remains vague and is unlikely to provide sufficient guidance for medical professionals seeking to use the HIPC to justify disclosure of genetic information. The wording reflects the use of this section in situations of external danger, rather than uncertain internal danger, like genetic threats.

Previous to Amendment No. 7, which came into force in April 2013, r 11 also included the requirement of "imminent". A reason for the removal of this requirement was that it limited the potential for these rules to include disclosure or use of genetic information.[53] The onset of genetic diseases can be hard to predict, and including a requirement for "imminent" may be too stringent. There is academic debate as to whether removing "imminent" in the HIPC has the intended effect of allowing discretion to disclose.[54] There is an argument that the third limb of the test inserts an implication of imminence.[55] In addition, while removing the requirement widens the scope of the rules, it remains limited by medicine's own professional standards.[56] It also does not provide guidance as to situations where it is appropriate to disclose information, leaving a lot of discretion and responsibility on medical professionals.[57] The HIPC gives limited support for doctors who wish to disclose information and this may leave them vulnerable to review and patient complaints.

[52] John McClellan & Mary-Claire King "Genetic Heterogeneity in Human Disease" (2010) 141(2) Cell 210 at 210
[53] Joanne Lee ""Serious" but not "imminent": genetics and the disclosure of health information to at-risk relatives" (2013) 126(1377) NZMJ 59 at 59
[54] At 60
[55] At 59
[56] Wee, above n 42, at 239
[57] Lee, at 60

c) A possible solution

One possible avenue for disclosing information in the HIPC, is r 11(1)(c): "that the disclosure of the information is one of the purposes in connection with which the information was obtained".[58] If the patient is informed before genetic testing that any information obtained from that testing may be passed onto relatives, then it can come under this exception.[59] This exception is not dependent on the patient consenting to the sharing of information obtained. However, under this rule patients may perceive the doctor to be sacrificing their privacy for their relatives' wellbeing, and this could have negative effects on the quality of the doctor-patient relationship. In addition, if the patient comes to their doctor armed with test results from direct-to-consumer genetic testing kits, then this exception may not apply.

d) Conclusion

The HIPC code is insufficient to provide assurance for medical professionals that they are able to legally disclose genetic information. The HIPC lacks sufficient guidance to give doctors confidence in determining whether disclosure is appropriate. The other possibility under the HIPC that allows disclosure is r 11(1)(c). However, that rule requires the patient to be notified before testing, which may not always be the case.

3. Common law

a) Breach of confidence

Breach of confidence is an equitable doctrine.[60] The English case *Coco v A N Clark (Engineers) Ltd*[61] is recognised in New Zealand as implementing the standard test for a breach of confidence. This test was articulated in *Hosking v Runting* and reaffirmed by the Supreme Court in *Rogers*.[62] The test as was stated in *Hosking*: [63]

(1) The information must have the necessary quality of confidence about it;
(2) The information must have been imparted in circumstances importing an obligation of confidence; and

[58] Health Information Privacy Code, r 11(1)(c)
[59] Wee, above n 42, at 239
[60] *P v D* [2000] 2 NZLR 591 (HC)
[61] *Coco v A N Clark (Engineers) Ltd* [1969] RPC 41
[62] *Hosking v Runting*, above n 44; *Rogers v Television New Zealand Limited* [2007] NZSC 91
[63] *Hosking v Runting*, at [26] per Gault and Blanchard JJ

(3) There must be an unauthorised use or disclosure of that information to the detriment of the party communicating it.

While this tort was traditionally invoked in commercial transactions, the case law has established that it covers information obtained from medical tests.[64] Courts have also confirmed that medical confidence is legally distinguished from medical privilege.[65]

The test requires a situation where there is confidence surrounding the information. The relationship between a medical professional and a patient is a fiduciary relationship and subject to the rules of confidentiality.[66] Thus, it would be a breach of confidentiality for a doctor to warn relatives of their patient about potential genetic risks when this knowledge has been obtained from the patient.

There must also be an unauthorised use or disclosure of that information to the detriment of the party communicating it. This is a detriment to the individual to whom the personal information relates to.[67] Unconsented disclosure of information about an individual's genetic condition to others is a breach of a fundamental principle of medical privacy: allowing people to regulate what personal information is available to other people.[68] Thus, disclosure without the consent of the patient violates personal autonomy, and would likely have some detrimental effect on the patient.

Overall, information about a patient obtained from genetic testing and disclosed to relatives without consent is very likely to fall under this tort. It has convincing analogies with established case law that concerns the disclosure of medical information obtained from medical procedures.[69]

b) Defences to the breach

[64] *Furness v Fitchett* [1958] NZLR 396 (SC); John Dawson "Health information law: General principles" in Peter Skegg & Ron Paterson (ed) *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015) 317 at [10.3.1]
[65] *Duncan v Medical Practitioners Disciplinary Committee* [1986] 1 NZLR 513 (CA) at 520
[66] At 521; Health Information Privacy Code 1994, r 11
[67] *Duncan v Medical Practitioners Disciplinary Committee*, above n 64
[68] Health Information Privacy Code 1994, r 11
[69] E.g. *Duncan v Medical Practitioners Disciplinary Committee*; *Furness v Fitchett*

(1) The public interest exception

The most relevant defence to a breach of confidence in this scenario is that the public interest in the information outweighs the duty to keep confidence.[70] This exception applies where the value of the information to the public interest outweighs the weight to the duty of confidentiality.[71] It is described as a balance between the interests of the private individual in keeping confidence, and the interests of the public in knowing the confidential information.[72] A leading English authority *W v Egdell* allowed this exception to be used to validate the disclosure of medical reports to authorities for a psychiatric patient who had committed violent crimes.[73] It supports the position that physical threats of harm are included under this exception.[74] This case has been cited in New Zealand as an authority for the confidentiality of medical reports.[75]

The High Court in *Duncan* confirmed that in New Zealand, medical confidentiality can be breached if there is a clear public interest in doing so.[76] The doctor must breach confidentiality and act to prevent harm to another if they have received information concerning a patient putting another person in immediate danger. In this instance, a doctor must "exercise his professional judgment based upon the circumstance", and if they "fairly and reasonably believe[s] such danger exists" then they must take action.[77] In this decision, an assessment of the proportionality of the factors is the appropriate appraising technique.[78] The substance of the information will affect the amount of public interest it has. It is then weighed in proportion against a breach of confidentiality.[79] With information of high value, it is more likely that the weight of public interest will be in proportion to the breach.

The case law sets a high bar for the public interest exception. Lord Denning concluded that the exception was relevant to crimes, as well as "frauds and misdeeds" that were intended or

[70] John Dawson "Common law of confidentiality, privacy and disclosure" in Peter Skegg & Ron Paterson (ed) *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015) 389 at [12.2.2]
[71] *European Pacific Banking Corporation v Television New Zealand* Ltd [1994] 3 NZLR 43 (CA) at 48 per Cooke P
[72] *R (s) v Plymouth City Council* [2002] EWCA Civ 388
[73] *R v Egdell* [1990] 1 All ER (CA) at 836
[74] J. K. Mason & G. T. Laurie *Mason and McCall Smith's Law and medical ethics* (8th ed, Oxford University Press, Oxford, 2011) at [6.25]
[75] *R v X* [2009] NZCA 531 at [38]
[76] *Duncan v Medical Practitioners Disciplinary Committee*, above n 65, at 521
[77] At 521
[78] *R v X*, above n 75, at [85]
[79] At [87]

committed.[80] The established exceptions appear to be rooted in external threats of tangible harm to others, rather than internal harm.[81] In addition, *Duncan* includes the requirement of "immediately endangered", which would exclude late onset genetic diseases and the consideration of future offspring.[82] The recipient of the information must be a "responsible authority", hence similar to the HIPC, the information cannot be disclosed to any arbitrary individual who has no power to use the information to mitigate harm.[83]

Whether this exception could encompass disclosure of genetic risks to relatives has not been established in New Zealand. Analogies can be drawn from New Zealand and international case law that could support a duty. Conversely, the cases could be distinguished by genetic information being too unpredictable to qualify. Thus, no definitive answer can be given as to whether this exception would apply, and if it did, there is little guidance as to what genetic circumstances it would apply.

4. A duty to warn

Medical professionals may be subject to a duty to warn, which is a duty owed to a third party. Doctors can be liable in negligence for a failure to breach confidentiality if they do not warn a likely victim that they may be in danger of harm from their patient.[84] The duty is only applicable in a narrow range of circumstances where the relevant risk is "imminent and serious", and it is necessary to breach confidentiality to warn the potential victim.[85] The test for deciding if a medical professional owes a duty of care to a third party is whether it is "fair, just and reasonable" for them to do so.[86] This decision takes into account the two broad ambits of proximity and policy considerations.[87]

a) Proximity

There must be proximity or a relationship between the medical professional and the third party who has suffered harm. It is more than just classic foreseeability, and can take into account

[80] *Initial Services Ltd v Putterill* [1968] 1 QB 396 (CA) at 405 per Lord Denning cited in *R v X*, above n 75, at [63]
[81] Charles Ngwena & Ruth Chadwick, "Genetic diagnostic information and the duty of confidentiality: Ethics and law" (1993) 1(1) Medical L Intl 73 at 81
[82] *Duncan v Medical Practitioners Disciplinary Committee*, above n 65, at 521
[83] At 521
[84] John Dawson, above n 70, at [12.5]
[85] At [12.5]
[86] *Couch v Attorney-General* [2008] NZSC 45 at [109]
[87] *Attorney-General v Prince and Gardener* [1998] 1 NZLR 262 (CA) at 268 cited in *Maulolo v Hutt Valley Health Corporation Ltd* [2002] NZAR 375 at [17]

duties established in analogous case law, as well as the competing moral claims.[88] It also requires that the patient pose "a particular threat to a particular individual or small group of individuals" or alternatively, that there is a "pre-existing duty to the victim".[89] The ability to identify and warn a potential victim is essential in considering whether a sufficient proximity or relationship exists.[90] For example, if there is an ability for the defendants to control the perpetrator, it is likely that a pre-existing duty of care for the victim will be recognised.[91]

The New Zealand cases of *Van de Wetering*, *Maulolo* and *Ellis* all failed to establish a close proximity or nexus between the victim and the defendant.[92] In *Van de Wetering*, the plaintiffs did not have a "unique", nor pre-existing, relationship with the Defendant that would justify a close proximity.[93] The Defendant also did not voluntarily assume responsibility for the plaintiffs; the plaintiffs were merely members of the public who were unfortunately involved in a traumatic event. Similarly, in *Maulolo* there was no relationship between the victim and her murderer before he was released from psychiatric care;[94] thus, she was not deemed to be a "threatened victim".[95] In *Ellis*, a proximate relationship could not be established between the health board and Mr. Ellis that would create a duty for the health board to detain Mr. Ellis against his will.[96] This is in contrast to *Couch*, where the Supreme Court decided that Ms Couch had an arguable case for proximity, as she was a former co-worker of Mr. Bell (the perpetrator of the violence against Ms Couch). She arguably had a "distinct and special risk" of suffering harm at the hands of Mr. Bell.[97]

In light of the case law, genetic disclosure is likely to involve a relationship of proximity. There is an identifiable person or group of people to warn, which would likely include immediate biological relatives. Some of these relatives may also have a professional relationship with the

[88] *Attorney-General v Prince and Gardener*, above n 86, at 268 cited in *Maulolo v Hutt Valley Health Corporation Ltd*, above n 87, at [17]
[89] *S v Midcentral District Health Board (No 2)* [2004] NZAR 342 at [22]
[90] *Palmer v Tees Health Authority* [1999] Lloyd's Rep (Med) 351
[91] *Ellis v Counties Manukau District Health Board* [2007] 1 NZLR 196 at [163]
[92] *Van de Wetering v Capital Coast Health* (High Court, Wellington, CP 368/98, 19 May 2000, Master Thomson); *Maulolo v Hutt Valley Health Corporation Ltd*, above n 85; *Ellis v Counties Manukau District Health Board*, above n 91
[93] *Van de Wetering v Capital Coast Health*, at 9
[94] *Maulolo v Hutt Valley Health Corporation Ltd*, at [9]
[95] At [25]; The term "threatened victim" came from the US case *Tarasoff v. Regents of University of California* 17 Cal. 3d 425 (1976)
[96] *Ellis v Counties Manukau District Health Board*, at [167]
[97] *Couch v Attorney-General*, above n 86, at [124]

doctor, increasing the likelihood of satisfying the proximity requirement.[98] It could be argued that in the paradigm case, the medical professional owes a duty to relatives of the patient since the doctor has contact with them as patients in their own right (e.g. *ABC*[99]).

b) Policy considerations

The second sphere consists of policy arguments for and against the imposition of a duty. These considerations tend to either support or weaken a duty that is established by proximity. A policy factor that opposes the imposition of a duty, is that it could limit the medical professionals' ability to keep their patients' best interests at the forefront. The potential liability from breaching the duty would encourage the medical profession to practice defensively.[100] For example, doctors may start to refuse to order genetic testing, or require the patient go to another doctor for genetic testing, in order to avoid a duty to warn relatives. This lack of support for testing may therefore have a chilling effect on patients getting tested for genetic conditions. Hence, as a by-product of the doctor protecting themselves from liability, the patient's interests become secondary to the interests of the doctor.[101]

Another policy factor against a duty is that the law is hesitant to put an unlimited duty on individuals, reiterating the deep-seated principle against imposing "liability in an indeterminate amount for an indeterminate time to an indeterminate class".[102] However, this may not be an issue for genetic information, as it is inherently limited by its familial nature. Therefore, there would be a determinate class of people to which the duty would be owed to.

The core policy factors that support a duty are aimed to ensure that doctors act professionally and maintain an acceptable standard of care for their patients. Doctors are "expected to exercise reasonable care and skill in carrying out their statutory functions"; thus a duty of care would be complementary to the statutory regime.[103] In addition, where the patients are particularly vulnerable, they are more reliant on a medical professional exercising reasonable care and

[98] Mark Henaghan *Genes, Society and the Future Volume II* (Human Genome Research Project, Dunedin, 2007) at 388
[99] *ABC*, above n 5
[100] *Van de Wetering v Capital Coast Health*, above n 92, at 16
[101] At 16-17
[102] *South Pacific Manufacturing Co Ltd v New Zealand Security Consultants & Investigations Ltd* [1992] 2 NZLR 282 at 295 per Cooke P cited in *Van de Wetering v Capital Coast Health,* at 19
[103] *Ellis v Counties Manukau District Health Board*, above n 91, at [170]

skill.[104] With many factors to consider, the policy arguments do not provide much clarity to the likelihood of whether a duty to warn could be imposed on medical professionals.

5. Conclusion

Within statutory instruments and the common law, there are possible avenues for medical professionals to disclose confidential information. However, these avenues either do not allow disclosure of genetic information to relatives, or do not guarantee that disclosure would not have legal consequences. New Zealand will need to change its legal landscape if it wants to provide medical professionals with guidance as to whether or not it is appropriate or not to disclose genetic information.

C. The United States of America

A foundational case that is cited in England and New Zealand, as well as in the United States, is *Tarasoff v Regents of University of California*.[105] This case established that a medical professional can owe a duty to warn a third party.

1. Tarasoff v Regents of University of California

a) The facts

In 1969 Prosenjit Poddar murdered Tatiana Tarasoff. Two months before this event, Poddar confided to his psychologist Dr. Moore, an employee at Cowell Memorial Hospital at the University of California at Berkeley, of his intention to kill Ms. Tarasoff. Ms. Tarasoff was given no warning by the Hospital or any of the therapists of the potential danger she was in.

b) The claim

The Plaintiffs (Ms. Tarasoff's parents) claim that Ms. Tarasoff's death proximately resulted from the Defendants negligently failing to warn Ms. Tarasoff of the harm.

c) The judgment

For the plaintiffs to establish a duty of care between Ms. Tarasoff and the Defendants, they need to establish the element of foreseeability. The general principle is that a "defendant owes a duty of care to all persons who are foreseeably endangered by his conduct, with respect to all

[104] *Ellis v Counties Manukau District Health Board*, above n 91, at [170]
[105] *Tarasoff v. Regents of University of California*, above n 95

risks which make the conduct unreasonably dangerous".[106] Generally, in common law there is no duty to control the conduct of another nor warn others of potential harm.[107] However, if there is a "special relationship" between the defendant and the dangerous person or their potential victim, there is a duty to warn of foreseeable harm.[108] Such a relationship between a psychologist and patient may support affirmative duties for the benefit of third persons.[109] Thus, a duty can be established between a medical professional and third party, even if they did not have any direct contact.[110]

Following the relevant professional practice standards, once a medical professional has reasonably determined that a patient presents a serious threat of harm to another, they are under a duty to "exercise reasonable care to protect the foreseeable victim of that danger".[111] Nevertheless, the Court acknowledged that how the duty can be discharged is fact-dependent. It may be satisfied by calling and warning the potential victim, calling the police, or taking reasonable steps necessary in the circumstances.[112] The decision to warn must take into account the public interest in protecting confidentiality, balanced against the prevention of potential harm to the public.[113]

2. Application of Tarasoff

Tarasoff was heavily cited by the Court of Appeal in *ABC*. The parallels between the two cases are undoubted, and the support that *Tarasoff* provides in *ABC* for the imposition of a duty is invaluable.[114] *Tarasoff* was also considered in *Maulolo* but not applied in the case. In New Zealand, the principle from *Tarasoff* to warn potential victims only applies to victims who are identified or foreseeable.[115]

3. Further developments

Two prominent cases regarding the failure to warn relatives of genetic risks is *Pate v Threlkel* and *Safer v Pack*.[116] *Pate* concerned a patient who had medullary carcinoma of the thyroid and

[106] *Tarasoff v. Regents of University of California*, above n 95, at [434] and [435]
[107] At [435]
[108] At [435]
[109] At [436]
[110] At [436]
[111] At [439]
[112] At [431]
[113] At [436]
[114] *ABC*, above n 5, at [56]
[115] Heron & Jordan, above n 46, at 139
[116] *Pate v. Threlkel* 661 So. 2d 278 (1995); *Safer v. Estate of Pack* 291 N.J. Super. 619 (1996)

her daughter who subsequently developed this cancer. The patient's daughter argued that her mother's medical professional was under a duty to warn the mother that her relatives may be at risk of developing the cancer, and that if she was warned, she could have taken preventative action.[117] The daughter was successful, and the Supreme Court of Florida held that the doctor was under a duty to warn the initial patient about risks of their relatives developing the disease.[118] The duty argued for in this case is slightly different from that of *Tarasoff* and *ABC*, in that the duty was owed to the patient, not to the third party. The duty would be satisfied when the doctor told his patient of the risks present to the patient's family, with the assumption that the patient will convey the message to their relatives.[119] This has been described as a 'weak' duty as it does not require relatives to be directly warned by the medical professional.[120]

Safer is closer to the factual situation in *ABC*. In *Safer* the question was whether doctors have a duty to disclose the risks of illness to their patient's relatives directly. In this case, the appellant suffered from metastatic colorectal cancer, which her father had also previously suffered from.[121] The appellant claims that at the time her father was being treated, it was known that the condition was hereditary, yet she was not warned of her risks of developing the disease. If she had known the risks, she would have benefited from close monitoring and early treatment.[122] In this instance, the appellant successfully argued that the foreseeability of the risk was sufficient to impose a duty onto the doctor to take reasonable steps to directly ensure that relatives are warned of their genetic risks.[123]

Safer imposes a higher duty than *Pate*. In *Safer*, a duty may not necessarily be discharged when the doctor only informs the patient of the risks, with the expectation that the patient will disclose that information to relatives.[124] The doctor may have to go further and ensure that the relatives are warned directly. This has been described as a 'strong' duty in the literature.[125] However, commentators have speculated that the reasoning in *Safer* is not comprehensive enough to be

[117] *Pate v. Threlkel*, above n 116, at [279]
[118] At [282]
[119] Ellen Wright Clayton "What Should the Law Say about Disclosure of Genetic Information to Relatives" (1998) 1 J. Health Care L. & Pol'y 373 at 384; Wee, above n 42, at 238
[120] C. Mitchell, M. C. Ploem, R. C. M. Hennekam & J. Kaye "A Duty To Warn Relatives in Clinical Genetics: Arguably 'Fair, just and reasonable' in English Law?" (2016) 32(2) Tottels J Prof Neglig 120 at 125
[121] *Safer v. Estate of Pack*, above n 116, at [622]
[122] At [623]
[123] At [629]; Also Dov Fox, Emily Spencer & Ali Torkamani "Returning Results to Family Members: Professional Duties in Genomics Research in the United States" (2018) 38(2) J Leg Med 201 at 210
[124] At [627]
[125] Mitchell et al., at 125

sufficient to establish an encompassing duty to disclose genetic risks, nor does the Court qualify its decision with policy considerations.[126]

As a result of these cases, many states have legislated on the scope of the duty. By 2018, at least 27 states have codified a mandatory duty on a therapist to protect potential victims, and 18 states have a permissive duty.[127] Some states have reversed the decision of *Safer* in legislation, barring medical professionals from disclosing confidential information to their patient's relatives without the patient's consent.[128]

4. Conclusion

The three leading cases from the United States present a strong basis for imposing a duty on doctors to warn. However, they lack guidance for identifying circumstances where it may be justifiable to breach confidentiality and disclose information. *Tarasoff* establishes a foundation on which disclosure may be justified. *Pate* does not directly address the issue of a duty to warn third parties but does support duties in the area of genetic information. *Safer* goes further than *Pate* to establish that the doctor may be required to warn third parties on some occasions.

D. Australia

Rather than leaving developments to common law, in 2006 Australia implemented statutory authority under s 16B(4) of the Privacy Act 1988 (Cth) for disclosure of genetic information to relatives. The section allows for medical professionals to have a discretion to breach confidentiality and inform their patient's relatives about genetic risks. The test for use or disclosure consists of:

> s 16B
>
> (4) A ***permitted health situation*** exists in relation to the use or disclosure by an organisation of genetic information about an individual (the ***first individual***) if:
>
> (a) the organisation has obtained the information in the course of providing a health service to the first individual; and
>
> (b) the organisation reasonably believes that the use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety of another individual who is a genetic relative of the first individual; and

[126] Wright Clayton, above n 119, at 388
[127] Ahmad Adi & Mohammad Mathbout "The Duty to Protect: Four Decades After Tarasoff" (2018) 13(4) Am J Psychiatry Resid J 6 at 7
[128] At 7

(c) the use or disclosure is conducted in accordance with guidelines approved under section 95AA; and
(d) in the case of disclosure—the recipient of the information is a genetic relative of the first individual.

This test does not place a duty on medical professionals to tell relatives, unlike the duties seen in common law.[129] It simply gives the medical professional a discretion to disclose information if it meets the requirements.[130]

1. The guidelines

To allow disclosure, there are nine guidelines that need to be complied with under s 95AA (see Appendix I). The guidelines establish circumstances when it may be appropriate for medical professionals to disclose information. It is important to note that these guidelines do not hold the same weight as legislation; however, they enable medical professionals to avoid complaints if they are followed closely.[131] The application of the guidelines are limited to those working in private practice.[132] In Guideline One, "life, health and safety" has a broad scope, including both physical and psychological health. In this assessment, the doctor may take into account situations where the disease is not treatable, if knowledge of the condition would help with the management of the disease and any psychological changes.[133]

a) Excluding unborn relatives

Amendments to the guidelines in 2014 confirm that any serious risks to unborn relatives are beyond the scope of the test.[134] In *Essentially Yours* (the report on which the guidelines are based) it was deemed that disclosure solely for the purpose of reproductive decisions was not a sufficient reason.[135] It stated that "the threat of harm through the exercise of reproductive choice is too remote to justify departure from existing privacy protection and duties of medical

[129] Tony Bogdanoski "Challenges to genetic privacy: The case of disclosure of genetic information to a patient's genetic relatives" (2008) 33(3) Alt L J 165 at 167
[130] National Health and Medical Research Council, above n 13, at 4
[131] Margaret F A Otlowski "Disclosing genetic information to at-risk relatives: new Australian privacy principles, but uniformity still elusive" (2015) 202(6) MJA 335 at 335
[132] At 335
[133] National Health and Medical Research Council, at 42
[134] At 6
[135] Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council "Essentially Yours: The Protection of Human Genetic Information in Australia" (14 March 2003) ALRC 96 at [21.80]

confidentiality".[136] This stance is also justified by the perceived lack of general agreement on the ethical position of pre-implantation genetic diagnosis (PGD), contraception and abortion.[137] Therefore, the guidelines do not account for future reproductive decisions of relatives, which can be the reason why people may want to know if they carry genetic risk factors.

The exclusion of unborn relatives creates a disconnect between *ABC* and what is covered in Australia. In *ABC*, harm to the Claimant's unborn child was a factor that led to a possible duty of care. However, under Australian guidelines this would not be an acceptable argument. The guidelines instead justify disclosure based on the adverse psychological effects on the mother, through having miscarriages or children who could have inherited disease-causing alleles.[138]

2. Conclusion

Australia has taken the most direct approach to developing this area of privacy law. With the establishment of a statutory test, supplemented by the guidelines, it gives medical professionals clarity in this situation and practical guidance on whether they should exercise discretion to disclose confidential information to relatives. Statutory guidance works to avoid the legal uncertainty that may hinder development in common law.

[136] Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council, above n 135, at [21.81]
[137] At [21.82]
[138] National Health and Medical Research Council, above n 13, at 59

III. Should there be a duty or a discretion to disclose?

The case law and legislative developments discussed above have been based on an analysis of what obligations doctors owe relatives. These decisions draw upon previous case law, and the rationales reflect fundamental medical privacy principles. However, there is a conflict between the two strongest principles: doctor-patient confidentiality, and the public interest in relatives knowing information about themselves. This balancing act is reflected in the common law: whether the public interest in disclosure can justify a breach of confidentiality. As New Zealand law has been vague on this topic, it would be helpful to have an analysis of the types of obligations that may be imposed on medical professionals.[139] This chapter will look at the difference between a duty to disclose information and a discretion, as well as options for alternative duties. It will examine the benefits and drawbacks of each option in the perspective of the parties involved.

A. A Duty

ABC and *Tarasoff* both allow the possibility of a duty of care on the medical professional to disclose information to third parties. Under the imposition of a duty, medical professionals have a legal obligation to inform the third party, even if it is against their patient's will.[140] If the duty of care is not discharged sufficiently, there can be legal liability in negligence. In addition to satisfying the three-fold *Caparo* test, a duty has only been imposed as a consequence of a "special relationship" between the healthcare professional and the third party.[141] In *ABC*, this was established by the Claimant participating in family therapy in the capacity of a patient of the Defendants.

The strongest theoretical argument for the imposition of a duty is the familial nature of genetics.[142] Unlike the majority of medical information about an individual, genetic information does not solely concern one individual; it is shared between biological relatives. Hence,

---

[139] Wee, above n 42, at 239

[140] Anneke Lucassen & Roy Gilbar "Disclosure of genetic information to relatives: balancing confidentiality and relatives' interests" (2018) 55(4) J Med Genet 285; Damon Muir Walcott, Pat Cerundolo & James C. Beck "Current analysis of the Tarasoff duty: An evolution towards the limitation of the duty to protect" (2001) 19 Behav Sci Law 325

[141] E.g. *ABC* and *Tarasoff*

[142] Roy Gilbar "The Passive Patient and Disclosure of Genetic Information: Can English Tort Law Protect the Relatives' Right to Know?" (2016) 30 IJLPF 79 at 79; Niklas Juth "The Right Not to Know and the Duty to Tell: The Case of Relatives" (2014) 42(1) J Law Med Ethics 38 at 44

information ascertained from one person's genome is relevant to close relatives who have a high chance of also possessing the relevant alleles. The right to know information about oneself is a recognised part of medical practice and ethics, and this may be a sufficient foundation to justify a duty.[143]

1. Perspective of the medical profession

A duty removes the ability of medical professionals to choose when to disclose genetic information. If the genetic risk factors meet the criteria for a duty, then the doctor must disclose the information, regardless of the patient's wishes. It may comfort patients to know that their doctor is not intentionally breaching confidentiality, instead there is an underlying legal obligation, similar to the required reporting of communicable diseases.[144] Consequentially, there may be less erosion of the trust between the doctor and patient.

Under a duty, the doctor must determine whether the criteria for disclosure is met. Therefore, a duty still has some element of professional evaluation to it. In order to minimise any uncertainty, the test for whether the criteria is met should be as objective as possible. Regardless, there will always be some subjective evaluation of the risks. An objective test is important to ensure that the outcome is not dependant on the doctor who applies it.

A drawback of a duty is that it places legal liability on medical professionals if they fail to inform relatives. This could lead to doctors practicing defensively, as articulated in the policy considerations in *Van de Wetering*.[145] In this situation, doctors would prioritise protecting themselves from legal liability, and consequentially, their patients' interests would become secondary to the their own. For example, doctors may start failing to request genetic testing of their patient in order to avoid a duty to relatives. Alternatively, they may avoid high risk patients altogether to reduce their chance of liability.[146] In addition, doctors may start considering the interests of relatives over those of the patient, in an effort to ensure that the duty to relatives is discharged.

---

[143] Jane Wilson "To know or not to know? Genetic ignorance, autonomy and paternalism" (2005) 19 Bioethics 492 at 492

[144] Health Act 1956, s 74(1)(a)

[145] *Van de Wetering v Capital Coast Health*, above n 92, at 16

[146] Jeri E. Reutenauer "Medical malpractice liability in the era of genetic susceptibility testing" (2000) 19(3) Quinnipac L Rev 539 at 573

Furthermore, doctors need to know at what point the duty has been discharged. This issue is discussed in both *Pate* and *Safer*. In *Pate*, the duty is discharged when the doctor warned the patient, whereas in *Safer*, the doctor must take reasonable steps to directly ensure the relatives are warned of potential risks. For a duty to be imposed, it must be clear as to when it is satisfied. A 'weak' duty would fall under the scenario in *Pate*, where there only a duty to inform the patient of genetic risks to relatives, while a 'strong' duty would follow the avenue of *Safer* and *ABC*, in that the doctor must warn relatives directly.[147] In this dissertation, the more relevant duty is a strong duty, as that is the one that breaches confidentiality. If any duty is imposed, a clear test is required so medical professionals can know when the duty has been discharged.

It is also worth noting that in *ABC*, Lord Irwin acknowledged that if there was no benefit to be gained from notifying a relative, then it may be a case where no duty is imposed.[148] Hence, in circumstances where it prima facie appears to be a situation where a duty is imposed, it may not be due to the relatives' personal situation. This places a burden on medical professionals to have knowledge of the relatives' wellbeing.

2. Perspective of patients

Patients could also benefit from a duty. If the duty covers the genetic information, it would provide certainty and predictability to doctors' actions. It may reassure patients that doctors have an underlying duty to disclose information, rather than it being solely the doctor's choice. It would also not be doctor-dependent whether genetic information would be disclosed, and so prospective patients cannot go "doctor shopping" to find one that will not disclose information to genetic relatives.

A duty puts the doctor in a difficult position; they are obliged to breach confidentiality with a patient to disclose information to that patient's relatives. Thus, a duty overrides the patient's choice, which is a fundamental part of patient autonomy and confidentiality. It also potentially undermines the trust that is built between a doctor and the patient.[149] Consequentially, disclosure of sensitive personal information may be discouraged, and patients may stop being forthcoming to doctors if they feel that this information is not safe. In fact, it may be that some

[147] Mitchell et al., above n 120, at 125
[148] Edward S. Dove, Vicky Chico, Michael Fay, Graeme Laurie, Anneke M. Lucassen & Emily Postan "Familial genetic risks: how can we better navigate patient confidentiality and appropriate risk disclosure to relatives?" 0 J Med Ethics 1 at 2
[149] Michael Parker & Anneke Lucassen "Genetic information: a joint account?" (2004) 329 BMJ 165 at 166

patients stop seeking treatment altogether.[150] The reluctance to share information may have a negative effect on the quality of healthcare received by patients.

3. Perspective of the relatives

The main benefit of imposing a duty is that it ensures that relatives who may be at-risk are informed of this fact. If alerted of their risks, they can mitigate the effects of the disease and prepare for its onset. In addition, it is possible that relatives will feel betrayed if they discover that their doctor knew of relevant genetic risks and did not inform them.

A situation where a relative may benefit from being informed of genetic risks, is familial cancer. For example, families can carry BRCA1 or BRCA2 breast cancer mutations. BRCA mutations only account for 15-20% of familial breast cancer, but it has an incredibly high penetrance. Individuals with a BRCA1 mutation have upwards of an 80% chance of developing breast cancer by the age of 70, as well as an increased risk of ovarian cancer.[151] Knowledge that a family carries a specific BRCA mutation is beneficial, as it means that preventative action can be taken (e.g. preventative mastectomy and prophylactic ovary removal), as well as increased monitoring so that cancer can be detected early. In the future, knowledge of genetic defects that contribute to cancer may allow for specialised cancer treatment, which targets the specific mutation.[152] Hence, there can be significant benefits for relatives if they are informed of genetic risks.

Knowledge of possible risks will also influence reproductive decisions, as argued in *ABC*. Although reproductive decisions were not recognised by the Australian guidelines as an acceptable reason for disclosure, it is arguably an important reason why people want to know about genetic risks. It is possible that people who knowingly carry risk alleles choose not to

[150] Anneke Lucassen & Michael Parker "Confidentiality and serious harm in genetics – preserving the confidentiality of one patient and preventing harm to relatives" (2004) 12 Eur J Hum Genet 93 at 94

[151] D. Ford D. F. Easton, M. Stratton, S. Narod, D. Goldgar, P. Devilee, D. T. Bishop, B. Weber, G. Lenoir, J. Chang-Claude, H. Sobol, M. D. Teare, J. Struewing, A. Arason, S. Scherneck, J. Peto, T. R. Rebbeck, P. Tonin, S. Neuhausen, R. Barkardottir, J. Eyfjord, H. Lynch, B. A. J. Ponder, S. A. Gayther, J. M. Birch, A. Lindblom, D. Stoppa-Lyonnet, Y. Bignon, A. Borg, U. Hamann, N. Haites, R. J. Scott, C. M. Maugard, H. Vasen, S. Seitz, L. A. Cannon-Albright, A. Schofield, M. Zelada-Hedman & the Breast Cancer Linkage Consortium "Genetic Heterogeneity and Penetrance Analysis of the BRCA1 and BRCA2 Genes in Breast Cancer Families" (1998) 62 Am J Hum Genet 676 at 677

[152] Hannah Farmer, Nuala McCabe, Christopher J. Lord, Andrew N. J. Tutt, Damian A. Johnson, Tobias B. Richardson, Manuela Santarosa, Krystyna J. Dillon, Ian Hickson, Charlotte Knights, Niall M. B. Martin, Stephen P. Jackson, Graeme C. M. Smith & Alan Ashworth "Targeting the DNA repair defect in BRCA mutant cells as a therapeutic strategy" (2005) 434 Nature 917; Michael J. Duffy, Naoise C. Synnott & John Crown "Mutant p53 in breast cancer: potential as a therapeutic target and biomarker" (2018) 170 Breast Cancer Res Tr 213

reproduce, or alternatively they may use reproductive technologies. In New Zealand, pre-implantation genetic diagnosis (PGD) is an established procedure for specific genetic diseases under the Human Assisted Reproductive Technology Order 2005.[153] Diseases include seriously impairing mendelian disorders, sex-linked disorders, familial chromosome disorders and aneuploidy. Therefore, relatives who carry deleterious risk alleles can use PGD to have children who will not be affected. Using PGD can also be cost-effective, as it removes the long-term medical treatment costs associated with the disease.[154]

a) A right not to know

A duty to disclose information to genetic relatives is beneficial for those relatives who wish to be alerted of any risks of disease, but it does not consider those who do not. There is a large body of literature and international documents supporting an individual's right not to know about medical information concerning themselves.[155]

The current position in medical ethics is that personal autonomy should be respected.[156] This means respect for an individual's right to make their own decisions, including the decision to remain ignorant of genetic risks.[157] However, there are many different interpretations in philosophy of what autonomy consists of.[158] John Stuart Mill advocated for respecting others decisions, without regard to the basis of those decisions, as long as there was no harm to another and the person possessed adequate maturity.[159] Thus, whether the decision was "foolish,

[153] ACART "Guidelines on Preimplantation Genetic Diagnosis with Human Leucocyte Antigen Tissue Typing" (18 August 2014)
[154] Lynn B. Davis, Sara J. Champion, Steve O. Fair, Valerie L. Baker & Alan M. Garber "A cost-benefit analysis of preimplantation genetic diagnosis for carrier couples of cystic fibrosis" (2010) 93(6) Fertil Steril 1793 at 1793
[155] Victoria Chico "Non-disclosure of genetic risks: The case for developing legal wrongs" (2016) 16(1-2) Med Law Int 3 at 21; Wilson, above n 143, at 492; Graeme T Laurie "In defence of ignorance: Genetic information and the right not to know" (1999) 6 Eur J Health Law 119 at 119; Maureen Durnin & Michael Hoy "Third Party Sharing of Genetic Information" in Sorin Hostiuc (ed) *Clinical Ethics At the Crossroads of Genetic and Reproductive Technologies* (Elsevier, United Kingdom, 2018) 385 at 391; E Asscher & B-J Koops "The right not to know and preimplantation genetic diagnosis for Huntington's disease" (2010) 36 J Med Ethics 30 at 30; Bell & Bennett, above n 7, at 132; Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Council of Europe, ETS 164 (4 April 1997), art 10(2); UNESCO Universal Declaration on the Human Genome and Human Rights 33 C/Resolution 15 (19 October 2005), art 5c
[156] An example is the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, Right 7
[157] R Andorno "The right not to know: an autonomy based approach" (2004) 30 J Med Ethics 435 at 435
[158] Roy Gilbar "Patient autonomy and relatives' right not to know genetic information" (2007) 26 Med Law 677 at 679
[159] Candace Cummins Gauthier "Philosophical foundations of respect for autonomy" (1993) 3(1) Kennedy Inst Ethics J 22 at 25; Raanan Gillon "Autonomy and the principle of respect in autonomy" (1985) 290 BMJ 1806 at 1807; Matti Häyry & Tuija Takala "Genetic information, rights, and autonomy" (2001) 22 Theor Med 403 at 411

perverse, or wrong" was irrelevant as long as there was no harm to another.[160] This principle of autonomy is ingrained within medical law, countering a history of medical paternalism that had been justified by consequentialist arguments.[161] Contrarily, in Kant's concept of autonomy, those who choose to remain ignorant cannot exercise their autonomy, as they do not possess all of the information available to that person.[162] Unlike Mill's theory of autonomy, Kant's argument disregards the right to ignorance and the benefit of that decision. Thus, while both arguments have merit in philosophy, based on current medical practice, Mill's theory would be a more appropriate lens to perceive what autonomy entails in this context. On this basis, it would be within the right of the relatives to have their wish to remain ignorant of genetic risks respected.

Knowledge of genetic risks can be burdensome, and relatives may wish to live without that knowledge hanging over their lives. The psychological impact of testing is serious and can lead to the development of psychological conditions, regardless whether the individual has the condition or not.[163] There is research which concludes that individuals may experience a lack of autonomy, anxiety, depression, negative self-image, discrimination and stigmatization, irrespective of the results of the testing.[164] In addition, studies show that individuals with a diagnosis of Huntington's disease have a higher rate of suicide.[165] It is noted in *ABC* that if the Claimant was more psychologically vulnerable, then it may have been acceptable for the doctors to withhold her father's diagnosis. It has also been suggested that non-carriers may in some cases also suffer the negative effects of survivor's guilt.[166] Therefore, it is reasonable that individuals may wish to avoid the stress of knowing their genetic risk status.

The problem that is encountered with a duty, is that it requires reasonable steps to be taken to inform relatives of their risks. This requirement undermines relatives' right not to know.

---

[160] Gauthier, above n 159, at 25
[161] Gauthier, at 28; Häyry & Takala, above n 159, at 411
[162] Gauthier, at 23; Juth, above n 142, at 40
[163] Asscher & Koops, above n 155, at 30
[164] Juth, above n 142, at 38
[165] Asscher & Koops, above n 155, at 30; Elisabeth W. Almqvist, Maurice Bloch, Ryan Brinkman, David Craufurd & Michael R. Hayden on behalf of an international Huntington disease collaborative group "A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalization after predictive testing for Huntington Disease" (1999) 64 Am J Hum Genet 1293 at 1293; Heather H. Wetzel, Carissa R. Gehl, Lisa Dellefave–Castillo, Judith F. Schiffman, Kathleen M. Shannon, Jane S. Paulsen & The Huntington Study Group "Suicidal ideation in Huntington disease: The role of comorbidity" (2011) 188 Psychiatry Res 372 at 374
[166] S Crozier, N Robertson & M Dale "The Psychological Impact of Predictive Genetic Testing for Huntington′s Disease: A Systematic Review of the Literature" (2015) 24 J Genet Counsel 29 at 30

Relatives have an ethical right not to know that there is a possibility that they are at risk of the disease, and any contact by a doctor to let them know they may be at risk would undermine that right. [167] When a medical professional asks whether the relative wishes to know the risks, they violate that right to ignorance.[168] Thus, a duty to disclose and the right not to know cannot be compatible, as one would need to give over to the other. The imposition of an *ABC*-type duty would likely introduce some medical paternalism, with the relative given no option but to know, regardless whether they wanted to or not.[169] To ignore the negative effects a duty would have on personal autonomy would be unwise.

Various opinions exist as to whether the duty to disclose should outweigh the relatives' right not to know. There are commentators that criticise the acknowledgment of relatives' right not to know, concluding that the duty to disclose has more weight than the right not to know the risks.[170] In *ABC*, Lord Irwin added that a putative right not to know did not preclude a duty of care.[171] Contrarily, advocates for relatives' rights argue that remaining ignorant is a practice in personal autonomy and should be respected over a duty to disclose.[172]

As a pillar of modern medicine, it would be an omission to disregard an individual's autonomy to choose to remain unaware of genetic risks. A duty on an individual should not be discharged only when the rights of another person has been breached (e.g. similar to the policy consideration against a duty of care in *South Pacific*, that the imposition of a duty would "cut across established principles of law in fields other than negligence").[173] Therefore, a duty would have to be carefully imposed to ensure that it has minimal negative impact on a relative's ethical right not to know.

4. Types of diseases where a duty may be appropriate

There may be situations where arguably the duty to disclose is arguably suitable. Conditions that are serious and are potentially treatable or preventable may become subject to a duty to disclose. For example, with genetically-based cancers, there are options for early detection and

[167] Bell & Bennett, above n 7, at 136
[168] Dorothy C. Wertz & John C. Fletcher "Privacy and disclosure in medical genetics examined in an ethics of care" (1991) 5(3) Bioethics 212 at 221
[169] Andorno, above n 157, at 436
[170] Wertz & Fletcher, at 222
[171] Dove et al., above n 166, at 2
[172] Andorno, above n 157, at 436
[173] *South Pacific*, above n 102, at 301

treatment, or preventative action. In this situation, notification of any risks would have benefits beyond the mere fact of knowledge.[174] Early detection and treatment increases the likelihood of survival and reduces the costs of cancer treatment.[175] The availability of treatment to lessen or prevent the genetic disease is a factor that leans towards disclosure, and this is reflected in Guideline One of the Australian Guidelines.[176] It is beneficial for the individual as well as for society that cancer is detected early, and this may tip the balance in favour of imposing a duty onto medical professionals.

5. Conclusion

The imposition of a duty has benefits and drawbacks for doctors, patients and relatives. It is difficult to come to an uncontentious conclusion on whether the imposition of a duty is appropriate. Relatives who wish to know and doctors would likely benefit the most from the imposition of a duty, while patients and those relatives who do not wish to be informed of genetic risks, would suffer the most. With respect to this, it is argued that the benefits of a duty cannot be ignored, and there is a place in medical law for a duty to be imposed.

B. Other possible duties

1. A duty to consider the interests of the relative

An alternate duty proposed by Dove et al., is a duty to consider the interests of genetic relatives. This duty requires that doctors balance relatives' interest in disclosure against the confidentiality of the information, to come to a justifiable decision.[177] This duty can therefore be discharged regardless of the decision. It would allow medical professionals to use their professional judgment to decide, on a case by case basis, whether a relative's interest in the information is sufficient to breach confidentiality. This duty allows medical professionals to act on their professional judgment, without fear of liability in negligence or breach of confidentiality. It does not impose a duty to disclose information. Within this discretion, medical professionals would use the relevant medical guidelines and duties to ensure that they act in accordance with good medical practice, which would help limit their legal liability.[178] This type of duty can consider a wide range of factors that influence a decision. It can

[174] Durnin & Hoy, above n 155, at 391
[175] World Health Organisation "Early guide to cancer diagnosis" (2017)
[176] National Health and Medical Research Council, above n 13, at 8 (See Appendix I)
[177] Dove et al., above n 166, at 1
[178] At 3

accommodate relatives' right not to know, the type of disease, the potential harm, whether treatment is available, the likely age of onset, and the significance to family members.[179] Alternatively, it may be possible to have a duty to make a reasonable decision. Under this version, medical professionals must account for the interests of relatives and the patient, to make a decision that is reasonable in the circumstances.

The difficulty with these types of duties, is that this is an area of law and medicine where reasonable people can disagree on the best course of action. Therefore, guidance would be necessary to achieve uniform decision-making and ensure that there is some certainty for the parties involved. An issue with this duty for relatives and patients is that decisions may be hard to review. Doctors would benefit from legal protection if they acted in accordance with ethical and professional good practice.[180] Therefore, due to its complexity, this duty may not be appropriate to implement.

C. A discretion

Unlike a duty, a discretion to disclose would impose no legal liability on medical professionals for failing to disclose. This is the approach taken in Australia under s 16B(4) of the Privacy Act and the corresponding guidelines under s 95AA. These sections only facilitate a discretion to disclose information to relatives, not a duty to disclose.[181] The guidelines provide medical professionals a criteria through which they can utilise clinical judgment and evaluate whether confidentiality can be breached. The report, *Essentially Yours*, that fuelled the legislative change in Australia, did not support the imposition of a duty to warn. Rather, it favoured giving medical professionals discretion.[182]

Previous to *ABC*, in English law and bioethics there had been a general agreement that doctors should have no legal duty to inform genetic relatives; instead they possessed a discretion to breach their patient's confidentiality.[183] It had been described as an "intermediate position", halfway between non-disclosure and a duty to disclose information.[184]

---

[179] Dove et al., above n 166, at 3
[180] At 3
[181] National Health and Medical Research Council, above n 13, at 4
[182] Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council, above n 135, at [21.51]
[183] Roy Gilbar "Communicating genetic information in the family: the familial relationship as the forgotten factor" (2007) 33 J Med Ethics 390 at 390
[184] Mireille Lacroix, Gillian Nycum, Béatrice Godard & Bartha Maria Knoppers "Should physicians warn patients' relatives of genetic risks?" (2008) 178(5) CMAJ 593 at 594

1. Perspective of the medical profession

A discretion to disclose would allow medical professionals to avoid a legal obligation to disclose genetic information. They would therefore avoid legal liability for failing to disclose. In a scenario with unlimited discretion, medical professionals would also avoid all forms of liability. However, an unlimited discretion is unlikely to be used in practice. It is more likely that discretion would be limited, so that a medical professional would be liable for an unjustified breach of confidentiality.

A discretion could allow medical professionals to take into account a wider range of factors, which a duty may ignore, such as the reason for not wanting disclosure. Therefore, in accordance with best medical practice, medical professionals can make a decision that considers the wider circumstances of the case.[185] For example, with a discretion, medical professionals would not be hamstrung by an obligation to disclose if they believe it would not be appropriate. It also removes the burden on physicians to need to find and contact relatives to warn.[186] Lastly, a discretion removes the need for regulations that specify how much information needs to be disclosed to discharge a duty.[187]

In practice, a discretion does have its drawbacks. A discretion to disclose information limits review of doctors' decisions, because there is no duty to discharge. There is a lack of accountability for doctors who fail to inform relatives of risks. For example, the Australian test allows a discretion to disclose. However, it imposes no liability if the doctor chooses not to disclose the information, even if it may be arguably allowed under the test. Therefore, situations like *ABC* would not be reviewed, as there is no duty to disclose even if there was good reason to. In scenarios where the doctor values confidentiality over disclosure, it is within their ambit to not disclose any relevant information to genetic relatives. However, if there is a legal limit to the discretion, there may be liability for an unjustified disclosure against legal guidelines.

[185] Gilbar, above n 183, at 391; Lacroix et al., above n 184, at 594
[186] Jeffrey W. Burnett "A Physician's Duty to Warn a Patient's Relatives of a Patient's Genetically Inheritable Disease" (1999) 36(2) Hous L Rev 559 at 579; Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council, above n 135, at [21.49]
[187] Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council, at [21.50]

When doctors make the decision to disclose, they bear the weight of that decision. It is arguable that doctors should not bear this burden, as it is a serious decision with many knock-on effects. Either way the decision goes, there is likely someone who will feel as though they have had their rights violated. With disclosure it will be the patient, or with non-disclosure it would be a relative who believed they had the right to know. This puts the doctor in a precarious position where they must take responsibility for the choice they make. Unlike under the imposition of a duty, a doctor who discloses information cannot say that the decision was out of their hands.

2. Perspective of patients

The benefit for patients would be that their right to confidentiality would not be automatically breached; therefore, the patient may be more willing to get genetic testing done.[188] If the patient has valid reasons for why they refuse to disclose to family members, that can be respected under a discretion to disclose. For example, if a patient has a son who may be at risk from a genetically-related disease, but the son has severe mental illness, this may be a valid reason for the patient refusing to consent to his son being alerted of potential genetic risks. If the son was informed about the potential genetic risks, it may have a severe negative psychological impact.[189] In that case, the detrimental consequences would likely be higher than any benefits obtained. Thus, disclosure would be harder to justify. This type of scenario was acknowledged in *ABC* as one that may not attract a duty, and it could be a valid consideration supporting non-disclosure.[190]

A negative aspect is that disclosing information under a discretion may erode patient trust, even more so than disclosure under a duty. Patients would know that their doctors are choosing to disclose information against the patients' wishes. Under a discretion, a doctor has no requirement to breach confidentiality. If they do so, it may result in a greater loss of trust from the patient than it would under a duty. Hence, there could potentially be greater negative impacts for patients under a discretion than under a duty.

3. Perspective of relatives

[188] Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council, above n 135, at [21.49]
[189] Theresa M. Marteau & Robert T. Croyle "Psychological responses to genetic testing" (1998) 316(7132) BMJ 693 at 595 at 203
[190] *ABC*, above n 5, at [38]

A discretion would likely be more beneficial to relatives as it is more compatible with the principle of autonomy. From a professional relationship between the doctor and relative, the doctor can ascertain the relative's views. Thus, with a discretion, a relative's right not to know could be incorporated into the evaluation of whether to exercise that discretion to disclose information. It is stated in *Essentially Yours* that if the information will likely have an adverse impact on the recipient, then disclosure should be avoided.[191] With a discretion, known negative impacts can be taken into account by doctors when deciding whether it would be appropriate to breach confidentiality.

A discretion can also take into account the concept of a 'relational perception of autonomy'.[192] In genetics this involves considering the wider impacts that disclosure would have on family dynamics and relationships.[193] This approach is designed to allow the medical professional to reach a sensitive decision that incorporates a range of interests that relations have, outside genetic risks to health. It is also in consonance with the attitudes of the health professionals and patients involved, as doctors' decisions whether or not to disclose to relatives can be heavily based on familial dynamics.[194]

With a discretion to disclose, there are no guarantees that the relatives would be informed of any genetic risk factors, including those for diseases that have treatments. For example, in Australia, there is no liability for failing to disclose information even if it passes the statutory test. Therefore, medical professionals who are against disclosure would not be required to disclose information in any circumstances. This can be an issue for relatives who would like to be informed of disease risks, especially for cancers where it may be possible to mitigate and treat the condition.

4. Conclusion

As with a duty, a discretion has benefits and drawbacks for doctors, patients and relatives. Thus, it is difficult to form a conclusive argument for or against allowing a discretion. A limited discretion offers doctors more flexibility and the ability to utilise their clinical judgment. This is beneficial as it allows doctors to consider a wide range of factors. However, there is no legal

[191] Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council, above n 135, at [21.49]
[192] Gilbar, above n 183, at 390
[193] At 390
[194] At 390

remedy available for relatives if the doctor chooses not to disclose the information. Consequentially, it is argued that a discretion may have a place filling in the gaps in situations that are outside the ambit of a duty.

IV. Possible Solutions Going Forward

This chapter will review regulatory options and work to build a possible framework for disclosure. The overall aim of this chapter is to attempt to find a system that provides certainty, while leaving doctors some degree of flexibility when required.

A. The joint account model

The joint account model was first suggested by Parker & Lucassen as an alternative to the traditional personal account model of medical information. The joint account model is based on the same premise as a joint bank account, in that all the information should be available to all the account holders, unless there is a valid justification for withholding information.[195] Hence, under the analogy, one holder of the account cannot ask the bank manager to withhold information from the other account holders. Under this model, family registries of information would be formed, and access given to genetic relatives. Thus, it would enable those who are pre-symptomatic to have testing for risk alleles that are prevalent in their family pedigree.[196]

This system is supported by ethical principles of familial justice and reciprocity. Genetics are inherently familial, so there is no reason why some members of the family should benefit from genetic knowledge and yet exclude other family members from those same benefits.[197] In addition, the sharing of genetic information would ensure that potential benefits are gained by a greater number of people, thereby reducing overall harm.[198] This model complements clinical practice. Geneticists often work with families, and with a joint account model of information, members of the family will have access to information and testing.[199] This approach both reduces overall harm and preserves the possibility of patient anonymity.

This model has been approved by other academics in this area as a viable option for accessing genetic information, and it may be possible for courts to adopt this approach.[200] This model is a reflection of the current position of familial perspective adopted by the United Kingdom

[195] Parker & Lucassen, above n 149, at 166
[196] At 166
[197] At 166; Also see *ABC*, above n 5, at [28]
[198] At 166
[199] At 166
[200] Charles Foster, Jonathan Herring & Magnus Boyd "Testing the limits of the 'joint account' model of genetic information: a legal thought experiment" (2015) 41 J Med Ethics 379 at 382

General Medical Council, and it could be imported into the *Bolam* test.[201] It has also been argued that a version of the joint account model, coupled with the idea of relational autonomy, may be a workable option in managing genetic information within families.[202]

However, critiques have been made on this original model that highlight the differences between a banking context and genetic context. Mainly, that although an individual may have access to the joint account, they would be unlikely to access the information without someone giving them warning of potential harm.[203] There will also be questions as to who may access the information in the joint account. For example, whether those who do not carry the risk allele still have access to the family account, and whether parents have access to their children's information. The model also does not differentiate between the penetrance of the risk alleles, or the degrees of genetic separation of extended family.[204] The accounts would also get unwieldy, as individual family accounts will cross over with each generation and leave individuals subject to multiple accounts. As well, the information available will continue to increase as new causal genes are discovered. Additionally, it may be subject to illegal hacking and data breaches, resulting in the information becoming available to the public.

1. Conclusion

The joint account model has many benefits, but the criticisms of it are valid. There is no guarantee that individuals will check their account of their own volition, and the amount of information in each account could become overwhelming over time. Thus, at this stage of the model's development, it would be practically difficult to integrate it into the healthcare system.

B. A national register

As established previously, the right to autonomy is crucial in medicine, and relatives' right not to know should be respected.[205] This runs into issues with any notification to a relative who wishes not to know the risks. Just the contact by a healthcare professional gives the relative

[201] *Bolam v Friern Hospital Management* Committee [1957] 2 All ER 118 at 122 "A doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art… Putting it the other way round, a doctor is not negligent, if he is acting in accordance with such a practice, merely because there is a body of opinion that takes a contrary view"; Foster et al., above n 200, at 382

[202] Foster et al., at 382

[203] At 380

[204] S M Laio "Is there a duty to share genetic information?" (2009) 35 J Med Ethics 306 at 308

[205] It becomes more compliant with Right 7(7) "Every consumer has the right to refuse services and to withdraw consent to services"

indication that they are at risk. A practical solution around this issue would be the creation of a national register, where relatives indicate whether they wish to be notified about genetic risks. Thus, individuals can elect whether or not to receive notification of genetic risks before any risks become apparent in their family.

1. The design

The system would be based on the presumption that a relative would be notified of any risks, but they can elect to opt out of notification. In practice, this information could be gathered by placing a notification box on admission sheets in GP clinics or hospitals. The information gathered would then be placed on a national register, so that in future if the opportunity to notify the individual presents itself, the register can be checked to confirm whether the person wishes to be notified or not. Generally, anyone over the legal age to give consent (e.g. 16 years in New Zealand)[206] would be able to make the choice.

To mitigate the issue of vagueness,[207] it could be possible to categorise which risks the person wishes to become aware of. Each individual could elect to opt out of notification for specific categories of diseases. One potential categorisation of conditions that could be used is:

> I wish not to be notified of:
>
> (1) The possibility of carrying risk alleles that contribute to diseases with established treatments (e.g. cancer)
> (2) The possibility of carrying risk alleles that contribute to diseases with management options but no cure (e.g. cystic fibrosis, haemophilia)
> (3) The possibility of carrying risk alleles that contribute to diseases with no established treatments (e.g. Huntington's disease, Duchenne muscular dystrophy)

In this model, individuals can opt out of all, any or none of the options for notification depending on their personal views. The categories are based on the availability of disease treatments, and are intended to respect individuals who wish not to know specific risks (e.g. if the individual does not wish to know risks for terminal diseases, but would like to know risks for diseases that have established treatments). The individual would also have the opportunity

[206] Care of Children Act 2004, s 36

[207] E.g. vagueness is a reason why choosing to put organ donor on a drivers' licence is not sufficient consent to organ donation

to update their status any time they fill out an admittance sheet or by contacting their GP clinic, as long as they provide a signature to the changes. Hence, if their views change, they can amend their status on the national register.

The terminology of "established treatments" would mean treatments that are widely accepted by the medical community and utilised in practice. So alternative, novel or developing treatments would not be considered an "established treatment". In addition, identification of individuals would be by their National Health Index (NHI) number, which also gives access to the individuals' demographic details. This includes the individuals' address through which contact can be made if necessary.

The information on the register would not be public. To manage access to the information it may be possible to have a system that is similar to the LandOnline property registration system. With LandOnline, law firms need to buy a licence to have access to change title registration. Similarly, in this situation a clinic will buy a licence and authorise specific people to have access the database. It could also have a digital certificate, so it keeps track of everyone who accesses the database.[208]

2. Issues

The implementation of a national register would face many issues due to the scope of the project. It involves a huge information database, which would be time-consuming to create and manage, as well as expensive. Thus, it leads to the next issue of who would fund such a register. Ultimately the responsibility would be on the Government, under the Ministry of Health, to oversee its creation and management. However, the health benefits obtained from the register may not justify the expense of implementation and management, as it would not have substantial medical information on it.

The register is also time consuming for GP clinics. The authorised person would need to possess the relative's NHI number, find them on the database, check whether or not they wish to be notified, and then proceed accordingly. As a solution to this problem, it may be possible to create an organisation that the doctor can contact for assistance. Armed with information from the doctor, the organisation could access the register and decide whether the relative should be

[208] Land Information New Zealand "Digital certificates and security" <https://www.linz.govt.nz/land/landonline/digital-certificates-and-security>

contacted. They could also organise contact with the relative. Another issue is that relatives may not appreciate all that their decision to opt out of notification entails and make a quick decision without considering the implications. The implementation of a national register is a balance between the value that society gives to the right not to know, and the time and cost it would entail to create and manage it.

3. Conclusion

If disclosure is permitted, it is likely that the pressure to impose notification protocols will only increase. A notification register would be the most practical way to respect individual autonomy and the right not to know, but it would be a large, expensive endeavour. Whether this option is feasible to implement will require a holistic view of the factors.

C. Statutory guidelines

For regulation of disclosure, statutory guidelines would provide the greatest amount of clarity. Guidelines can account for a multitude of different scenarios to help medical professionals balance different factors and come to reasoned decisions. Furthermore, the implementation of guidelines from Parliament is more democratic and allows the inclusion of different opinions through Parliamentary debate and public participation. Judicial decisions, on the other hand, have no avenue for public participation. Using Parliamentary processes can also allow for the guidelines to be amended, to maintain compatibility with medical developments.

1. New Zealand response to Australian guidelines

After the Australian statutory test and guidelines came into force, in 2007 the New Zealand Privacy Commissioner consulted on a proposed amendment to the HIPC that would give doctors a discretion to disclose information, in limited circumstances, to genetic relatives.[209] However, the proposal was not implemented as the Commissioner declined to proceed with the amendment, as the HIPC had the capacity to allow disclosure. The HIPC allows disclosure if the patient was notified before testing that any information obtained may be passed onto relatives without the patient's consent.[210] This exception to patient confidentiality relies on the medical professional consulting the patient on this possibility before any testing has taken place. It also does not account for people who go to their doctor with the results from direct-to-

[209] Wee, above n 42, at 238

[210] At 239; Health Information Privacy Code, r 11(1)(c) "the disclosure of the information is one of the purposes in connection with which the information was obtained"

consumer testing kits. New Zealand did not delve further into the possibility of adopting guidelines on this issue. It has now been over 10 years since this decision, and the genetic testing technology has progressed, as has the identification of genetic components in disease. Thus, it is important to revisit the idea of creating statutory guidance for medical professionals.

2. Possible guidelines

Both a duty and a discretion have positive and negative outcomes. However, combining the two may work to minimise the negative impacts. In this model, there would be a limited duty to disclose genetic information to relatives, and there would be an overall general discretion to disclose. This model aims to incorporate the flexibility that a discretion offers, with a duty to ensure people are notified when there is a valid reason.

a) A duty

The inclusion of a duty would be beneficial for mitigating the pressure on doctors of deciding whether to disclose. A duty should be "strong" to ensure that relatives are contacted when appropriate, but also limited, and based on clear guidelines to avoid confusion of when it applies. A narrow test, where only certain explicit genetic diseases attract a duty, gives clarity, but it is not very flexible for a long-term test. It would therefore be of long-term value to have a wider test that is not based explicitly on the type of genetic disease. A wider test is preferred because it gives more flexibility for the inclusion of newly discovered genetic risk alleles.

A possible statutory test for the imposition of a duty is:

(1) There is a proximate relationship between the doctor and relative; and[211]
(2) Disclosure of the information would benefit the relative in life, health or safety; and
(3) The relative is not known to have any contra-indications that would indicate an adverse effect if the information was communicated; and[212]
(4) The condition is a serious risk to the health of the relative[213]

[211] Based on the "special relationship" or proximate relationship from the test of negligence seen in *Tarasoff* and *ABC*
[212] E.g. mental health issues, cognitive issues, any indication they do not wish to be notified. This issue was discussed in *ABC v St Georges* at [38]
[213] This limits disclosure to penetrant, mendelian diseases

The proposed test aims to integrate the proximity element from *Caparo*, the psychological wellbeing of the relative as discussed in *ABC*, and the Australian statutory test and guidelines on the serious risk to health and degree of relative. The first requirement of a proximate relationship is to ensure that there is some professional, or close relationship, between the doctor and relative. This requirement is intended to ensure that there is a limit to whom the doctor owes a duty to, so relatives that the doctor has no contact with, do not come under the duty.

The Australian guidelines and statutory test state that disclosure without consent is justified because it "is necessary to lessen or prevent a serious threat to life, health or safety of a genetic relative".[214] In the second requirement, the criteria is inverted so that instead of a negatively worded test, the requirement that it brings a benefit to the relative in life, health or safety. The benefit to the relative justifies the breach of confidentiality with the patient. This version of the test is slightly more open, so doctors can consider a wide range of positive consequences of disclosure.

It is important that relatives should also be extended to include unborn relatives. As seen in *ABC* and in general literature, passing on risks to unborn children is a serious concern of the general public. With IVF and PDG becoming increasingly available, if people are notified of genetic risks there are methods to circumvent passing on risk alleles to offspring. The inclusion of unborn relatives is critical for ensuring that recessive and sex-linked disorders are captured under the duty. Sex-linked conditions are diseases that are carried on the X or Y chromosomes, and such diseases tend to have a sex-skewed presentation. For example, if a female carries a recessive X-linked disease like Duchenne muscular dystrophy, it would not present a serious risk to her health, but if she has a son, he has a 50% chance of inheriting the risk allele and a serious condition with no known cure. This test should encompass these types of situations so that actions can be taken to mitigate the negative possibilities.

The third requirement is intended to allow doctors to consider any potential negative consequences of the disclosure of information. Factors to consider could include knowledge of the psychological state of the relative, whether they wish not to know genetic risks, and any other factors that may mean that disclosure would result in no benefit being conferred.

[214] National Health and Medical Research Council, above n 13, at 34

However, it is possible that this requirement will dilute the purpose of the statutory test. As it has a broad ambit, doctors may start to use this section to conclude that the duty does not apply, when it reasonably does.

The fourth requirement is designed to restrict the duty to serious conditions, where disclosure should not be subject to the medical professional's own opinion. "Serious" is intended to only include genetic risk factors with mendelian inheritance or are highly penetrant. The statutory test works on the premise that the benefit received by the relatives justifies the breach of confidentiality to the original patient.

b) Beyond the duty

If a condition does not fit the criteria of a duty, then it would come within a discretion for disclosure. Whether a medical professional utilises their discretion could be based on guidelines similar to Australia. With a criteria to pass, the discretion will not be unlimited. There will also be the possibility of liability for disclosing information without justification. In general, a discretion can have a less rigorous criteria, and it may be an option to allow a discretion if there is a less proximate relationship between the doctor and relative. This could be useful in situations where the doctor has contact with the patient's family but owes no duty of care to them. The Australian guidelines extend the option of disclosure to third degree relatives.[215]

A discretion to disclose information about diseases that are less serious, allows medical professionals to utilise their judgment on deciding the best course of action. This would become more relevant with risk alleles that are less penetrant, contribute to a mild disease, or are part of a complex disease with multiple genetic and environmental factors. Genes are continuing to be discovered that contribute to a range of diseases, from psychiatric conditions like schizophrenia, major depressive disorder and autism spectrum disorder,[216] to diabetes and cardiovascular disease.[217] In these situations, knowledge of genetic risk factors may not have a benefit to relatives that would justify a breach of patient confidentiality. Hence, the ability for doctors to have a discretion to disclose is important.

[215] National Health and Medical Research Council, above n 13, at 8
[216] Daniel H Geschwind & Jonathan Flint "Genetics and genomics of psychiatric disease" (2015) 349(6255) Science 1489 at 1489
[217] The Wellcome Trust Case Control Consortium, above n 4, at 661

As in a duty, unborn relatives who may be at risk should be a consideration under a discretion. In addition, if there is any information available that indicates that a relative does not wish to be notified of any genetic risks, this should also be taken into consideration. While a preference for non-notification is a serious consideration when deciding whether to disclose, it would be impractical for doctors to take it as a veto to notification.

There may also be a protection provision that covers reasonable and good faith mistakes. In situations where the doctor believed that they had the consent of the patient, or that they fulfilled the criteria when they did not, this provision covers them from liability.

D. The effect of the NZMA Code of Ethics

All members of the New Zealand Medical Association (NZMA) are required to comply with the NZMA Code of Ethics.[218] The Code of Ethics sets out principles and recommendations of ethical practice, with emphasis on the social contract that the medical profession has with their community.[219] The code is based on key concepts of patient autonomy and the individual nature of healthcare. It does not take into account the shared nature of genetics and the increasing use of genetic information in medicine. If legal changes were adopted that allowed a duty or discretion to disclose genetic information, the code must also be amended to remain compatible with the law.

E. Conclusion

With so many different types and presentations of genetic-based conditions, it is difficult to articulate a test or construct a framework that can encompass all the elements and still be applicable in the future. The regulations also need to be practical so that medical professionals can apply them in clinical situations. The above proposal is merely one attempt at constructing a statutory test. It aims to retain the rigidity and accountability of the duty, while maintaining the flexibility that a discretion offers.

[218] New Zealand Medical Association "Code of Ethics: For the New Zealand medical profession" (May 2014) <https://www.nzma.org.nz/publications/code-of-ethics>
[219] At 2

Conclusion

This issue of medical confidentiality will only become more prevalent as genetic testing increases. The familial and predictive nature of genetics challenges the foundational privacy principles of medicine, and doctors may be faced with conflicting ethical obligations. Thus, New Zealand needs to address whether medical professionals should be able to breach confidentiality and inform their patient's relatives of genetic risks.

The landmark English case, *ABC*,[220] has shown that the courts are willing to tackle this issue directly using the common law. New Zealand has made some attempts to address this issue under the HIPC, but it has for the most part been left unresolved and unclear to practitioners. The doctrine of breach of confidence and the common law duty to warn both include medical scenarios. However, no cases have been bought forward that directly address non-consensual genetic disclosure. Therefore, based on the current case law, it would be unlikely that disclosure of genetic information would be allowed.

In addition to the United Kingdom, the United States and Australia have also responded to the issue of disclosure. In the United States, a duty to warn was first implemented in *Tarasoff*, with an extension to genetic information confirmed in the form of a weak duty in *Safer* and a strong duty in *Pate*. Australia specifically legislated on this exact issue with a statutory test and legislative guidelines, which allows a discretion for medical professionals to disclose to relatives. These international developments give New Zealand a lot to draw upon and consider when deciding how to proceed on this issue.

If disclosure is allowed, the central issue is whether to give medical professionals a duty or a discretion to disclose information. There are many factors to consider, and each avenue has benefits and detriments for doctors, patients and relatives. There is no perfect answer that would benefit all parties. However, a combination of both a duty and discretion may incorporate the best of both options. In serious situations a duty would provide certainty, and in other circumstances a discretion would allow doctors to use clinical judgment to come to an appropriate decision.

[220] *ABC* , above n 5

Developing a framework for the future is difficult, and there are many different ways academics and jurisdictions have approached this issue. One method in the literature is the joint account model by Parker & Lucassen.[221] This model's familial view of genetic information is appropriate; however, the model itself would be difficult to implement.

A method that could be used in the framework is a national register for notification. This register would be used to solve issues associated with relatives' autonomy. On the register, individuals can record whether they want to be notified about their risks for certain types of conditions. Thus, doctors can respect this choice when deciding whether to notify relatives.

Based on international developments and available literature, imposing a statutory framework would be the most comprehensive way of regulating this area. A combination of a duty and discretion-based approach would encompass the benefits of both. The imposition of a statutory test for a duty gives clarity, and it can be implemented with some confidence by the medical community. For less severe genetic diseases, a discretion still applies that gives doctors flexibility to consider a wide range of factors and use their own professional judgment. This dissertation has given one example of how a statutory test may be formulated, but there are a multitude of ways this issue can be approached.

[221] Parker & Lucassen, above n 149

Appendix I

Use and disclosure of genetic information to a patient's genetic relatives under Section 95AA of the Privacy Act 1988 (Cth) Guidelines for health practitioners in the private sector

A: The Guidelines

Guidelines for the use or disclosure of genetic information without consent

The Guidelines are presented here for easy reference. The Guidelines provide a concise outline of the requirements for acting in accordance with APP 6.2(d) and section 16B(4) of the Privacy Act. They should be read in conjunction with the full explanation; page references are provided in brackets.

For the purposes of APP 6.2(d) and section 16B(4) of the Privacy Act:

Guideline 1: Use or disclosure of genetic information without consent may proceed only when the authorising medical practitioner has a reasonable belief that this is necessary to lessen or prevent a serious threat to the life, health or safety of a genetic relative.

Guideline 2: Specific ethical considerations must be taken into account when making a decision about whether or not to use or disclose genetic information without consent.

Guideline 3: Reasonable steps must be taken to obtain the consent of the patient or his or her authorised representative to use or disclose genetic information.

Guideline 4: The authorising medical practitioner should have a significant role in the care of the patient and sufficient knowledge of the patient's condition and its genetic basis to take responsibility for decision-making about use or disclosure.

Guideline 5: Prior to any decision concerning use or disclosure, the authorising medical practitioner must discuss the case with other health practitioners with appropriate expertise to assess fully the specific situation.

Guideline 6: Where practicable, the identity of the patient should not be apparent or readily ascertainable in the course of inter-professional communication.

Guideline 7: Disclosure to genetic relatives should be limited to genetic information that is necessary for communicating the increased risk and should avoid identifying the patient or conveying that there was no consent for the disclosure.

Guideline 8: Disclosure of genetic information without consent should generally be limited to relatives no further removed than third- degree relatives.

Guideline 9: All stages of the process must be fully documented, including how the decision to use or disclose without consent was made.

F. Legislation

1. New Zealand

Care of Children Act 2004
Privacy Act 1993
Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996
Health Information Privacy Code 1994

2. Australia

Privacy Act 1988 (Cth)

G. Cases

1. New Zealand

Attorney-General v Prince and Gardener [1998] 1 NZLR 262 (CA)
Cory Alexander Urlich v New Zealand Police [2019] NZHC 457
Couch v Attorney-General [2008] NZSC 45
Duncan v Medical Practitioners Disciplinary Committee [1986] 1 NZLR 513 (CA)
Ellis v Counties Manukau District Health Board [2007] 1 NZLR 196
European Pacific Banking Corporation v Television New Zealand Ltd [1994] 3 NZLR 43 (CA)
Furness v Fitchett [1958] NZLR 396 (SC)
Henderson v Privacy Commissioner [2010] NZHC 554
Hosking v Runting [2005] 1 NZLR 1 (CA)
Lehmann v Canwest Radioworks Ltd Decision No 35-06, HRRT 8-04 Sep 21, 2006
Maulolo v Hutt Valley Health Corporation Ltd [2002] NZAR 375
Mitchell v Privacy Commissioner [2017] NZHC 569
P v D [2000] 2 NZLR 591 (HC)
Rogers v Television New Zealand Limited [2007] NZSC 91
R v X [2009] NZCA 531
S v Midcentral District Health Board (No 2) [2004] NZAR 342
South Pacific Manufacturing Co Ltd v New Zealand Security Consultants & Investigations Ltd [1992] 2 NZLR 282
Van de Wetering v Capital Coast Health (High Court, Wellington, CP 368/98, 19 May 2000, Master Thomson)

2. United Kingdom

ABC v St George's Healthcare NHS Trust and others [2017] EWCA Civ 336 (CA)
Bolam v Friern Hospital Management Committee [1957] 2 All ER 118
Caparo Industries plc v Dickman [1990] 2 AC 605 (HL)
Coco v A N Clark (Engineers) Ltd [1969] RPC 41
Initial Services Ltd v Putterill [1968] 1 QB 396 (CA)
Palmer v Tees Health Authority [1999] Lloyd's Rep (Med)
R v Egdell [1990] 1 All ER (CA) at 836
R (s) v Plymouth City Council [2002] EWCA Civ 388

3. The United States of America

Pate v. Threlkel 661 So. 2d 278 (1995)

Tarasoff v. Regents of University of California 17 Cal. 3d 425 (1976)
Safer v. Estate of Pack 291 N.J. Super. 619 (1996)

H. Books

John Dawson "Privacy and disclosure of health information" in Peter Skegg & Ron Paterson (ed) *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015)

John Dawson "Health information law: General principles" in Peter Skegg & Ron Paterson (ed) *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015)

John Dawson "Common law of confidentiality, privacy and disclosure" in Peter Skegg & Ron Paterson (ed) *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015)

Maureen Durnin & Michael Hoy "Third Party Sharing of Genetic Information" in Sorin Hostiuc (ed) *Clinical Ethics At the Crossroads of Genetic and Reproductive Technologies* (Elsevier, United Kingdom, 2018)

Mark Henaghan *Genes, Society and the Future Volume II* (Human Genome Research Project, Dunedin, 2007)

J. K. Mason & G. T. Laurie *Mason and McCall Smith's Law and medical ethics* (8th ed, Oxford University Press, Oxford, 2011)

I. Journal articles

Ahmad Adi & Mohammad Mathbout "The Duty to Protect: Four Decades After Tarasoff" (2018) 13(4) Am J Psychiatry Resid J 6

Elisabeth W. Almqvist, Maurice Bloch, Ryan Brinkman, David Craufurd & Michael R. Hayden on behalf of an international Huntington disease collaborative group "A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalization after predictive testing for Huntington Disease" (1999) 64 Am J Hum Genet 1293

R Andorno "The right not to know: an autonomy based approach" (2004) 30 J Med Ethics 435

E Asscher & B-J Koops "The right not to know and preimplantation genetic diagnosis for Huntington's disease" (2010) 36 J Med Ethics 30

Sam Behjati & Patrick S Tarpey "What is next generation sequencing?" (2013) 98 Arch Dis Child Educ Pract Ed 236

Dean Bell & Belinda Bennett "Genetic Secrets and the Family" (2001) 9 Med Law Rev 130

Belinda Bennett "Genetic secrets and the family" (2001) 9 Med Law Rev 130

Tony Bogdanoski "Challenges to genetic privacy: The case of disclosure of genetic information to a patient's genetic relatives" (2008) 33(3) Alt L J 165

Jeffrey W. Burnett "A Physician's Duty to Warn a Patient's Relatives of a Patient's Genetically Inheritable Disease" (1999) 36(2) Hous L Rev 559

Victoria Chico “Non-disclosure of genetic risks: The case for developing legal wrongs” (2016) 16(1-2) Med Law Int 3

Angus Clarke, Martin Richards, Lauren Kerzin-Storrar, Jane Halliday, Mary Anne Young, Sheila A Simpson, Katie Featherstone, Karen Forrest, Anneke Lucassen, Patrick J Morrison, Oliver W J Quarrell, Helen Stewart & collaborators “Genetic professionals’ reports of nondisclosure of genetic risk information within families” (2005) 13 Eur J Hum Genet 556

Ellen Wright Clayton “What Should the Law Say about Disclosure of Genetic Information to Relatives” (1998) 1 J. Health Care L. & Pol'y 373

Francis S. Collins, Michael Morgan & Aristides Patrinos “The Human Genome Project: Lessons from
Large-Scale Biology” (2003) 300 Science 286

S Crozier, N Robertson & M Dale “The Psychological Impact of Predictive Genetic Testing for Huntington′s Disease: A Systematic Review of the Literature” (2015) 24 J Genet Counsel 29

Lynn B. Davis, Sara J. Champion, Steve O. Fair, Valerie L. Baker & Alan M. Garber “A cost-benefit analysis of preimplantation genetic diagnosis for carrier couples of cystic fibrosis” (2010) 93(6) Fertil Steril 1793

Edward S. Dove, Vicky Chico, Michael Fay, Graeme Laurie, Anneke M. Lucassen & Emily Postan “Familial genetic risks: how can we better navigate patient confidentiality and appropriate risk disclosure to relatives?” 0 J Med Ethics 1

Michael J. Duffy, Naoise C. Synnott & John Crown “Mutant p53 in breast cancer: potential as a therapeutic target and biomarker” (2018) 170 Breast Cancer Res Tr 213

Hannah Farmer, Nuala McCabe, Christopher J. Lord, Andrew N. J. Tutt, Damian A. Johnson, Tobias B. Richardson, Manuela Santarosa, Krystyna J. Dillon, Ian Hickson, Charlotte Knights, Niall M. B. Martin, Stephen P. Jackson, Graeme C. M. Smith & Alan Ashworth “Targeting the DNA repair defect in BRCA mutant cells as a therapeutic strategy” (2005) 434 Nature 917

D. Ford D. F. Easton, M. Stratton, S. Narod, D. Goldgar, P. Devilee, D. T. Bishop,
B. Weber, G. Lenoir, J. Chang-Claude, H. Sobol, M. D. Teare, J. Struewing, A. Arason, S. Scherneck, J. Peto, T. R. Rebbeck, P. Tonin, S. Neuhausen, R. Barkardottir, J. Eyfjord, H. Lynch, B. A. J. Ponder, S. A. Gayther, J. M. Birch, A. Lindblom, D. Stoppa-Lyonnet, Y. Bignon, A. Borg, U. Hamann, N. Haites, R. J. Scott, C. M. Maugard, H. Vasen, S. Seitz, L. A. Cannon-Albright, A. Schofield, M. Zelada-Hedman & the Breast Cancer Linkage Consortium “Genetic Heterogeneity and Penetrance Analysis of the BRCA1 and BRCA2 Genes in Breast Cancer Families” (1998) 62 Am J Hum Genet 676

Charles Foster, Jonathan Herring & Magnus Boyd “Testing the limits of the ‘joint account’ model of genetic information: a legal thought experiment” (2015) 41 J Med Ethics 379

Dov Fox, Emily Spencer & Ali Torkamani "Returning Results to Family Members: Professional Duties in Genomics Research in the United States" (2018) 38(2) J Leg Med 201

Lainie Friedman Ross "Genetic exceptionalism vs paradigm shift: Lessons from HIV" (2001) 21(2) J Law Med & Ethics 141

Candace Cummins Gauthier "Philosophical foundations of respect for autonomy" (1993) 3(1) Kennedy Inst Ethics J 22

Daniel H Geschwind & Jonathan Flint "Genetics and genomics of psychiatric disease" (2015) 349(6255) Science 1489

Roy Gilbar "Communicating genetic information in the family: the familial relationship as the forgotten factor" (2007) 33 J Med Ethics 390

Roy Gilbar "Patient autonomy and relatives' right not to know genetic information" (2007) 26 Med Law 677

Roy Gilbar "Between unconditional acceptance and responsibility: should family ethics limit the scope of reproductive autonomy?" (2009) 21 Child & Fam L Q

Roy Gilbar "The Passive Patient and Disclosure of Genetic Information: Can English Tort Law Protect the Relatives' Right to Know?" (2016) 30 IJLPF 79

Roy Gilbar & Sivia Barnoy "Disclosure of genetic information to relatives in Israel: between privacy and familial responsibility" (2012) 31(4) New Genet Soc 391

Roy Gilbar & Charles Foster "It's arrived! Relational autonomy comes to court: *ABC v St George's Healthcare NHS Trust* [2017] EWCA 336" (2017) 26(1) Med Law Rev 125

Raanan Gillon "Autonomy and the principle of respect in autonomy" (1985) 290 BMJ 1806

Jacob Gratten, Naomi R Wray, Matthew C Keller & Peter M Visscher "Large-scale genomics unveils the genetic architecture of psychiatric disorders" (2014) 17(6) Nat Neurosci 782

Matti Häyry & Tuija Takala "Genetic information, rights, and autonomy" (2001) 22 Theor Med 403

Michael Heron & Amy Jordan "Health professionals and mandatory reporting" (2001) N Z Law J 139

The Huntington's Disease Collaborative Research Group "A novel gene containing trinucleotide repeat that is expanded and unstable on Huntington's disease chromosomes" (1993) 72 Cell 971

Niklas Juth "The Right Not to Know and the Duty to Tell: The Case of Relatives" (2014) 42(1) J Law Med Ethics 38

Mireille Lacroix, Gillian Nycum, Béatrice Godard & Bartha Maria Knoppers "Should physicians warn patients' relatives of genetic risks?" (2008) 178(5) CMAJ 593

S M Laio “Is there a duty to share genetic information?” (2009) 35 J Med Ethics 306

Graeme T Laurie “In defence of ignorance: Genetic information and the right not to know” (1999) 6 Eur J Health Law 119

Joanne Lee ““Serious” but not “imminent”: genetics and the disclosure of health information to at-risk relatives” (2013) 126(1377) NZMJ 59

Anneke Lucassen & Michael Parker “Confidentiality and serious harm in genetics – preserving the confidentiality of one patient and preventing harm to relatives” (2004) 12 Eur J Hum Genet 93

Anneke Lucassen & Roy Gilbar “Alerting relatives about heritable risks: the limits of confidentiality” (2018) 361 BMJ 1

Anneke Lucassen & Roy Gilbar “Disclosure of genetic information to relatives: balancing confidentiality and relatives’ interests” (2018) 55(4) J Med Genet 285

Theresa M. Marteau & Robert T. Croyle “Psychological responses to genetic testing” (1998) 316(7132) BMJ 693

John McClellan & Mary-Claire King “Genetic Heterogeneity in Human Disease” (2010) 141(2) Cell 210

C. Mitchell, M. C. Ploem, R. C. M. Hennekam & J. Kaye “A Duty To Warn Relatives in Clinical Genetics: Arguably ‘Fair, just and reasonable’ in English Law?” (2016) 32(2) Tottels J Prof Neglig 120

Sonya Morgan, Deborah McLeod, Alexa Kidd & Barbara Langford “Genetic testing in New Zealand: the role of the general practitioner” (2004) 117(1206) N Z Med J 1

Charles Ngwena & Ruth Chadwick, "Genetic diagnostic information and the duty of confidentiality: Ethics and law" (1993) 1(1) Medical L Intl 73

Margaret F A Otlowski “Disclosing genetic information to at-risk relatives: new Australian privacy principles, but uniformity still elusive” (2015) 202(6) MJA 335

Michael Parker & Anneke Lucassen “Genetic information: a joint account?” (2004) 329 BMJ 165

Jeri E. Reutenauer "Medical malpractice liability in the era of genetic susceptibility testing" (2000) 19(3) Quinnipac L Rev 539

Rosamond Rhodes “Genetic links, family ties and social bonds: rights and responsibilities in the face of genetic knowledge” (1998) 23(1) J Med Philos 10

Damon Muir Walcott, Pat Cerundolo & James C. Beck “Current analysis of the Tarasoff duty: An evolution towards the limitation of the duty to protect” (2001) 19 Behav Sci Law 325

Richman Wee "Disclosure of genetic information to at-risk relatives: privacy law and professional guidance in New Zealand" (2011) 3 JPHC 237

The Wellcome Trust Case Control Consortium "Genome-wide association study of 14,000 cases of seven common diseases and 3,000 shared controls" (2007) 447 Nature 661

Dorothy C. Wertz & John C. Fletcher "Privacy and disclosure in medical genetics examined in an ethics of care" (1991) 5(3) Bioethics 212

Heather H. Wetzel, Carissa R. Gehl, Lisa Dellefave–Castillo, Judith F. Schiffman, Kathleen M. Shannon, Jane S. Paulsen & The Huntington Study Group "Suicidal ideation in Huntington disease: The role of comorbidity" (2011) 188 Psychiatry Res 372

Jane Wilson "To know or not to know? Genetic ignorance, autonomy and paternalism" (2005) 19 Bioethics 492

J. Official Documents

1. New Zealand

ACART "Guidelines on Preimplantation Genetic Diagnosis with Human Leucocyte Antigen Tissue Typing" (18 August 2014)

New Zealand Medical Association "Code of Ethics: For the New Zealand medical profession" (May 2014) <https://www.nzma.org.nz/publications/code-of-ethics>

2. Australia

National Health and Medical Research Council "Use and disclosure of genetic information to a patient's genetic relatives under Section 95AA of the Privacy Act 1988 (Cth)" (2014) PR3

Australian Law Reform Commission & Australian Health Ethics Committee of the National Health and Medical Research Council "Essentially Yours: The Protection of Human Genetic Information in Australia" (14 March 2003) ALRC 96

3. International documents

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Council of Europe, ETS 164 (4 April 1997)

UNESCO Universal Declaration on the Human Genome and Human Rights 33 C/Resolution 15 (19 October 2005)

World Health Organisation "Early guide to cancer diagnosis" (2017)

K. Websites

Land Information New Zealand "Digital certificates and security" <https://www.linz.govt.nz/land/landonline/digital-certificates-and-security