

**GENETICS AND FAMILIAL RISK**  
*ESTABLISHING THE CLINICIAN'S DUTY TO DISCLOSE*

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## ABSTRACT

The increasing accessibility of personal genetic information creates new challenges for the English Legal System. One of these challenges is the familial nature of genetic information, as screening one individual reveals information about their family unit as a whole. There are potential benefits to disclosing this information, the most important of which is facilitating access to preventative therapies and early treatment. This thesis considers whether clinicians should be subject to a duty to disclose genetic information to those members of a patient's family who are at the highest risk of sharing genetically transmissible conditions. It is suggested that such a duty could be created through the Tort of Negligence and that such a duty would be consistent with the underlying aims of the tort. This thesis considers the constituent parts of a claim in Negligence – duty, breach and causation – and suggests how these components might be interpreted to, firstly, create a duty to disclose and then, secondly, to give meaningful content to any such a duty. The thesis considers both domestic case law and jurisprudence from America, where a duty to disclose has been created by the courts, and considers whether a similar approach is permissible in English Law. It also examines the current paradigm of confidentiality and data protection and explains why the present legal framework is inadequate and does not provide sufficient legal protection for the relatives of patients harmed as a consequence of nondisclosure. It is the aim of this thesis to advance the debate on the legal implications of the familial aspect of genetic diagnosis and the role of the common law in tackling this challenge. It is also the first work to provide an in depth analysis of a potential duty to disclose genetic risks to the families of patients.

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*For those who didn't get to see me get this far.*

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*'We used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes.'*

- James Dewey Watson, former director, National Centre for Human Genome.

## **OVERVIEW**

The increasing accessibility of genetic information poses new challenges for the English Legal System. This is because genetic information is simultaneously personal and familial: when an individual undergoes genetic screening, the results reveal information about both the patient's genetic heritage and that of their family. This duality represents a significant challenge to current legal paradigms. Medico-personal data has traditionally been treated as confidential because it holds relevance only for the patient, however, genetic information can potentially provide clinicians with insight into the long-term health of whole families. An inherited disease might therefore be identified early and treated preemptively to prevent the condition eventuating or, in the alternative, to reduce the overall risk that the disease will occur. For example, if a member of a family is identified as being at risk of breast cancer, relatives who may share that risk could be forewarned, creating an opportunity for them to obtain screening and, if necessary, chemoprevention or a mastectomy.

There is no doubt that disclosing genetic risks within a family unit represents an opportunity to improve and protect long-term health when a treatment is available for the identified condition. An important question is how should the law respond to this familial aspect of genetic information. Should the courts adhere to a paradigm of patient confidentiality or should they recognise that disclosure is necessary in particular circumstances to avoid or minimise harm? This thesis proposes that the courts should adopt the latter approach and argues disclosure could be achieved through recognition of a tortious duty to disclose genetic risks to the patient's immediate family. It is argued here that when treatments are available for a disease, nondisclosure harms those family members who 'share' the patient's deleterious genetic trait.

In absence of statutory regulation, the law of tort will be the route for those wishing to bring a claim concerning the nondisclosure of genetic risks. The tort of negligence is an appropriate vehicle for this task. Its traditional role is to recognise and remedy harms inflicted upon individuals and indicate the appropriate standards of behaviour across a broad range of circumstances. These circumstances include medical practice and disclosure, thus a duty concerning genetic risks would not represent a wholesale expansion of the scope of negligence, although it may be portrayed as a radical amendment to the existing law.

This thesis is a doctrinal study. It will focus on how liability for the nondisclosure of genetic risks may be recognised through adaptation of the tort of negligence. The thesis comprises seven chapters.



Chapter one provides an overview of the science fundamental to the argument: it discusses the familial nature of genetics, patterns of inheritance and the potential benefits of disclosure. Chapter two examines the issues arising in respect of data protection and confidentiality. It explores different approaches to genetic information and doctor-patient confidentiality, the current legal framework and when disclosures are presently considered justifiable. It argues a confidentiality and data protection paradigm may permit disclosure of genetic information by reference to a public interest and considers which public interests might favour disclosure in this context. The chapter concludes by outlining why – if disclosure is possible within the current legal paradigm – a tortious duty should be preferred to a confidentiality model.

Chapter three examines the fundamentals of the duty of care. It also considers the attitude of the courts to non-physical harm, citing claims for psychiatric injury as a potential indication of the response of the courts to claims arising from the nondisclosure of genetic risks. The chapter then focuses on the scope of the duty to disclose to patients, which is a crucial element in defining the scope of a duty to relatives, because such must compliment the existing legal obligation. The duty to disclose to relatives cannot be articulated in broader terms than the clinician's duty to their patients. Finally, the chapter examines judicial responses to disclosure to third parties both domestically and in the United States and what these decisions may mean for a duty to disclose.

How claimants may go about establishing a duty to disclose is then considered in chapter four and five. Chapter four focuses on the concept of harm and explores possible definitions attributable to harm in the context of genetic nondisclosure. It posits that, despite current thinking, genetic conditions may constitute harm in negligence. Chapter five explores the issue of proximity, or neighbourhood, and how this requirement may be satisfied through demonstrating that the claimant is an identifiable victim. It also considers whether it is fair, just and reasonable to impose a duty and examines potential policy issues that may militate for or against creating a duty to disclose genetic risks.

The question of breach is the focus of chapter six, which begins by examining the current approach to breach in medical negligence claims and the problems presented by a test predicated on common practice. The chapter then considers whether breach should be approached in a way similar to that developing in cases on patient disclosure and if this approach would be fairer to claimants. Chapter seven considers the difficulties of causation. It examines the different approaches employed by the courts over time – the 'but for test', loss of a chance and material contribution to risk – and whether or not each approach is appropriate method of establishing a causal link in claims arising involving nondisclosure.

It is argued here that disclosure to family members is appropriate in particular circumstances and that harm sustained as a consequence of a nondisclosure should be recognised by the courts. Through a considered examination of the existing law, it is the aim of this thesis to demonstrate that the tort of negligence is an appropriate and practical means for dealing with the familial and legal implications of the (non)disclosure of genetic information and risk.

## **1. Introduction**

### *From Anonymity to Prominence*

If the 20<sup>th</sup> Century was the atomic age – with scientific advancement during this period indelibly linked with nuclear physics – then the 21<sup>st</sup> Century may be the age of genomics. In first decade of the new millennium, genetic science has staked an impressive claim to the mantle of *the* pioneering science of this chapter of human history. In 2003, after fourteen years of international collaboration and billions of dollars of investment, the Human Genome Project (HGP) successfully completed mapping the entire human genome. The conclusion of the HGP represented a watershed moment in genetics, scientific and medical development hurtling along at breakneck pace in the subsequent years. The rapid nature of progress is characterised by the European Commission's provision of commercial approval for gene therapy for lipoprotein lipase deficiency in 2012, adopting a recommendation of the European Medical Agency.<sup>1</sup> This represented the first marketing authorisation for gene therapy within the EU and came only nine short years after the conclusion of the HGP, emphasising the speed of progress in medical genetics.

The high profile and widespread coverage of developments in modern genetics is a far cry from the quiet, humble beginnings of mankind's interest in his genes – a seminal study of the inherited traits of pea plants by Czech monk Gregor Mendel in 1866.<sup>2</sup> Overshadowed by the apocalyptic fury of the atomic bomb, throughout the 20<sup>th</sup> Century breakthroughs in genetic science were made quietly and rarely garnered significant public attention. The anonymity of genetics during this period is characterised by the discovery of the double helix structure of DNA (deoxyribonucleic acid) by James Watson, Francis Crick and Maurice Wilkins in 1953. Later described as 'one of the most significant

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<sup>1</sup> BBC News 'Gene Therapy nears approval in Europe' 20 July 2012; BBC News 'Gene therapy: Glybera approved by European Commission' 2 November 2012; European Medicines Agency 'European Medicines Agency recommends first gene therapy for approval', 20 July 2012, available at [http://www.ema.europa.eu/ema/index.jsp?curl=pages/news\\_and\\_events/news/2012/07/news\\_detail\\_001574.jsp&mid=WC0b01ac058004d5c1](http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2012/07/news_detail_001574.jsp&mid=WC0b01ac058004d5c1) (accessed 15 July 2014).

<sup>2</sup> Mendel observed that particular phenotypes – observable characteristics – occurred predictably through several generations of garden pea plants. His hybridisation experiments revealed the pattern of inheritance of several characteristics that manifested in two contrasting phenotypes (e.g. height, which manifested as tall and dwarf). Mendel's research forms the basis of transmission genetics, sometimes called 'Mendelian Inheritance', which is used to explain the inheritance of autosomal dominant and autosomal recessive traits.

scientific discoveries of the 20<sup>th</sup> Century’, it led to the award of a Nobel Prize in 1962,<sup>3</sup> but scarcely made the headlines at the time.<sup>4</sup>

The beginning of the HGP – which was endorsed by the US National Research Council in 1988 and set up as an internationally coordinated study in 1990 – increased media coverage and public awareness of genetic science. It also coincided with a surge of interest in various genetic sciences in popular culture.<sup>5</sup> When it was announced in 2000 that the mapping of the entire double helical chain of DNA (stylised as ‘the master blueprint of us all’<sup>6</sup>) was 85 per cent complete, the milestone garnered significant attention. Notably, it commanded political attention, with then US President Bill Clinton and UK Prime Minister Tony Blair holding a joint news conference via a transatlantic satellite link. Mr Blair heralded the sequencing of the human genome as ‘[a] revolution in medical sciences whose implications far surpass even the discovery of antibiotics’ and ‘the first technological triumph of the 21<sup>st</sup> Century’.<sup>7</sup> Mr Clinton highlighted the importance and potential of genetic science, stating ‘[i]t’s possible that our children’s children will know cancer only as a constellation of stars.’<sup>8</sup>

### *Genes, Genetic Information and Genetic Testing*

The success of the HGP in 2003 concluded genetics rise from anonymity to prominence, ensuring that subsequent developments have become a regular fixture of mainstream news. A prominent area of scientific and medical advancement since the HGP has been genetic testing. Increasingly inexpensive methods of sequencing the human genome are being continually sought, the consequence being that ‘personal’ genetic information is becoming increasingly accessible and this could fundamentally change the manner in which

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<sup>3</sup> For more information, see NobelPrize.org ‘The Discovery of the Molecular Structure of DNA – The Double Helix, a scientific breakthrough’ available at [http://www.nobelprize.org/educational/medicine/dna\\_double\\_helix/readmore.html](http://www.nobelprize.org/educational/medicine/dna_double_helix/readmore.html) (accessed 26 July 2012).

<sup>4</sup> BBC News ‘Era of personalised medicine awaits’ 8 April 2009.

<sup>5</sup> Some notable examples of the use of genetic science as plot devices include *Jurassic Park* (1993) – cloning; *Gattaca* (1997) – eugenics; James Cameron’s *Dark Angel* (2000-2002) – transgenics and genetic engineering; and Sam Rami’s film reboot of the *Spiderman* franchise (2002-2007) – genetic engineering.

<sup>6</sup> US Department of Energy and National Institute of Health, *The Human Genome Project 1991-1992 Programme Report* (Office of Energy Research and Office of Environmental Research: Washington DC, 1992).

<sup>7</sup> BBC News ‘Leaders’ genetic code warning’ 26 June 2000.

<sup>8</sup> *Ibid.*

healthcare is delivered.<sup>9</sup> To provide a sense of the tumbling figures, the estimated cost of the HGP is between \$2 billion and \$3 billion; the cost of sequencing James Watson's genome in 2007 was \$1 million;<sup>10</sup> routine sequencing of cancer genomes has been estimated as costing \$30,000; and, in 2009, a company stated it would be capable of sequencing entire genomes for \$5,000.<sup>11</sup> The search for sequencing at a reduced cost may foreseeably allow medical practitioners to provide 'personalised medicine' through an understanding of individual patient's genomes. For example, drug treatments may be adapted to the specific individual as a result of pharmacogenomics – the study of the influence of genetics in responses to drugs. Taking account of the make up of the patient's genome, a treating physician could prescribe the most effective medication for that particular individual, 'personalising' the medical intervention.

Genetic testing is entering mainstream healthcare and the introduction of genomic medicine into the framework of the National Health Service (NHS) has had notable proponents. The government's advisor on genetics, Professor Sir John Bell, recommended in 2012 that the NHS back the genetic revolution,<sup>12</sup> and the House of Lords has previously called for greater integration of genetic medicine into mainstream healthcare.<sup>13</sup> Healthcare providers are also demonstrating a willingness to embrace the potential benefits of genetic technologies. In April 2012, the NHS initiated a pilot scheme extending the scope of neonatal genetic testing<sup>14</sup> and, in 2010, the Royal Brompton Hospital became the first NHS institution capable of screening the entire human genome.<sup>15</sup>

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<sup>9</sup> The development of cheaper sequencing techniques has been highly incentivised. The Archon X-Prize offered a \$10,000,000 prize to the first company that could sequence 100 genomes in ten days for \$10,000 or less: BBC News '£10m prize for super genetic test' 4 October 2006. A further \$10,000,000 prize was announced in 2012 requiring the genomes of 100 centenarians to be sequenced in 30 days at a cost no greater than \$1000 a genome: BBC News 'Genetic entrepreneur to compete in genomics X prize' 24 July 2012.

<sup>10</sup> Aldhous, P., 'Genome sequencing falls to \$5000' New Scientist (6 February 2009)

<sup>11</sup> *Ibid.*

<sup>12</sup> Human Genomics Strategy Group, *Building on Our Inheritance: Genomic Technology in Healthcare* (Department of Health: London, 2012).

<sup>13</sup> House of Lords Science and Technology Committee, *Genomic Medicine* (HMSO: London, 2009).

<sup>14</sup> BBC News, 'Newborn screening to be extended in pilot study' 8 April 2012. The pilot was a success and subsequently the extended screening programme has been rolled out across the United Kingdom.

<sup>15</sup> Royal Brompton & Harefield NHS Foundation Trust, "'Next Generation" Gene Sequencer to determine the genetic links of heart disease' 15 November 2010, available at <http://www.rbht.nhs.uk/media/press-releases/archive/gene-sequencer-to-determine-the-genetic-links-of-heart-disease/> (accessed 12 June 2012).

There can be no doubt that increasing accessibility of genetic information will pose significant challenges to established legal paradigms but a threshold question must be: what is meant by ‘genetic information’? Genes are the fundamental unit of hereditary, the building blocks of life that code proteins ‘essential to the construction and functioning of an organism.’<sup>16</sup> Defined broadly, genetic information can incorporate a potentially huge range of data: ‘information about what genes are, their number, variety, sequence or arrangement in a particular context, their function, the impact of that function (or non-function) upon the organism itself, and, relatedly, information about how gene expression affects phenotype.’<sup>17</sup> Taylor suggests that genetic information can be subdivided into two basic categories: ‘what is “is”, and what it “means”.’<sup>18</sup> The first is predominantly descriptive, defining the contours of an individual’s (or group’s) genomic architecture; the second is more interpretive, outlining the biological significance of a particular genetic make up. In the context of genetic testing and healthcare, it is the latter categorisation which is of interest, as it is this type of information that indicates what effect any given gene within the genome of the proband – the subject – will have. Of particular interest to this thesis are those genes that negatively impact an individual’s long-term health, either because a particular gene indicates a genetic disorder will eventuate at a future point, or there is an increased risk of a disorder developing during the proband’s lifespan.

Genetic information therefore has utility but it may also ‘be used to stigmatise’<sup>19</sup> and individuals could be prohibited from securing employment, seeking medical treatment or obtaining insurance premiums. These concerns have led commentators to question the suitability of the United Kingdom’s compartmentalised approach to Discrimination Law for tackling potential claims of genetic discrimination.<sup>20</sup>

A second legal conundrum will flow from the nature of genes and genetic information. At one and the same time, genes are personal and familial, thus genetic information will hold significance to both the proband and his or her blood relatives. This is because fifty per cent of an individual’s genome is inherited from their mother’s ovum

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<sup>16</sup> Taylor, M., *Genetic Data and the Law: A critical perspective on privacy protection* (Cambridge University Press, Cambridge: 2012), p. 44.

<sup>17</sup> *Ibid.*, p. 45.

<sup>18</sup> *Ibid.*

<sup>19</sup> Bill Clinton, above, n 8.

<sup>20</sup> See, for example, Waterstone, M., de Paor, A., ‘Forever in Blue Genes’ (2012) 106(1) GLSI 20; Thompson, A., ‘Genetic Discrimination’ (2008) SJ 152(26), 18.

and fifty per cent from their father's sperm, thus persons descending from a common gene pool can 'share' genetic traits. As Mendal observed in his pea plants, phenotypes – observable characteristics – will manifest vertically through generations, thus a parent and child can share height, eye colour, build and genetic risks. Consequentially, the results of a genetic test reveal information about both the proband's genome and the genetic heritage of his family. With genetic information becoming increasingly accessible, healthcare practitioners will foreseeably come into possession of information that is both pertinent to the health of their patient and that patient's family. If information about a treatable disorder is withheld then the patient's relatives may come to harm because they are unable to avail themselves of medical treatment, but if a disclosure is made then the clinician may be in breach of doctor-patient confidentiality. It is essential, then, that the law is equipped to adjudicate on potential claims arising from failures to disclose genetic information – specifically genetic risks – to those who may share elements of the patient's genome. As McClean explains, this type of difficulty has not arisen thus far because medical information has traditionally been 'regarded as falling into the sphere of privacy, protected by both data protection laws and the professional obligation of confidentiality ... because it usually only concerns no one but the patient him- or herself.'<sup>21</sup> However, the established paradigm is difficult to sustain insofar as genetic testing is concerned because genetic information is shared. Attempting to bring genetic information within the current legal framework on confidentiality is therefore likely to be unsatisfactory. This is because confidentiality cannot recognise any potential harms nondisclosure causes to the proband's blood relatives.

The complexity of scenarios involving genetic information is illustrated by the following example: a woman undergoes genetic testing and her results indicate that she is an asymptomatic carrier of the Haemophilia A gene. Providing that her father is not a haemophiliac, it can be presumed that her mother is also an asymptomatic carrier of the deleterious trait.<sup>22</sup> By sequencing the proband's genome her mother's genetic make up has also been revealed without the need for the mother to undergo testing. This raises an issue

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<sup>21</sup> McClean, S., *Autonomy, Consent and the Law* (Routledge-Cavendish: London, 2010) p. 155.

<sup>22</sup> Haemophilia is a recessive, sex-linked disorder that almost exclusively affects males. This is because the male XY chromosomal pair lacks the duplicate copy of the deleterious gene present in the female XX pairing. In the XX pairing, the non-faulty gene is dominant and expresses the associated phenotype (i.e. normal clotting). Haemophilia A affects an estimated one in 5,000 males. For more information, see [www.nhs.uk/Conditions/Haemophilia/Pages/introduction.aspx](http://www.nhs.uk/Conditions/Haemophilia/Pages/introduction.aspx) (accessed 26 July 2012).

of consent.<sup>23</sup> In addition, the proband's relatives – including, potentially, any partner or spouse – will be interested in her genetic information because (i) it is indicative of the content of their own genomes as they are descendants of a common gene pool, and (ii) because it has implications for their reproductive choices. The question therefore arises: should the proband's genetic information be disclosed?

This thesis is concerned with scenarios where the proband's genetic information has revealed treatable genetic risks and whether these risks should be disclosed to blood relations who may also possess the deleterious trait. For example, what if the proband's results in the above example indicated a predisposition to cancer? Disclosure of the patient's genetic information would apprise family members of a risk to their long-term health and present an opportunity to seek preemptive therapies. It is arguably in the interests of the many that genetic information is disclosed in such a scenario; in contrast, if an untreatable risk is identified there is less of an imperative to disclose because knowledge of the risk does not afford affected individuals the opportunity to avoid or minimise harm.<sup>24</sup>

It is axiomatic that the desire of blood relations to know of prospective risks to their health may not align with the proband's interest in medical privacy or the clinician's professional obligation of confidentiality. However, it is an interest that must not be ignored. The question is how the law should protect the family's interest in genetic risks and avoiding harm that may be minimised or averted entirely.

The response proposed by this thesis is the creation of a duty to disclose treatable genetic risks. Statutory intervention is presently unlikely thus it is proposed that a duty should be articulated through the tort of negligence. Negligence is accustomed to adjudicating on matters of clinical practice and the disclosure of risk, albeit thus far litigation has been generally restricted to disclosure within the doctor-patient relationship.<sup>25</sup> However, at first blush tortious intervention may appear unnecessary because: (i) arguably responsibility for dissemination of genetic information is a matter for

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<sup>23</sup> In that, if the mother is subsequently told of her carrier status, 'she is receiving information about her health as though she herself had been tested without her consent.' British Medical Association, *Medical Ethics Today: The BMA handbook of Ethics & Law*, 2<sup>nd</sup> ed. (BMJ Publishing: London, 2004), p. 315.

<sup>24</sup> The domestic courts appear to have acknowledged that a lack of benefit militates against disclosure of genetic information: see *Re YZ* [2013] EWHC Fam 935.

<sup>25</sup> For example, see *Sidaway v Bethlem Royal Hospital & Maudsley Hospital* [1985] AC 871; *Pearce v United Bristol Healthcare NHS Trust* [1999] 1 PIQR 53; *Chester v Afshar* [2005] 1 AC 134; *Birch v University College London Hospital* [2008] EWHC 2237; *Nadine Montgomery v Lanarkshire Health Board* [2010] CSOH 104.



the proband, and (ii) the duty of confidentiality already allows clinicians to disclose in breach of doctor-patient confidence when there exists ‘a countervailing public interest which favours disclosure’.<sup>26</sup> It is therefore possible to breach doctor-patient confidentiality when the proband is unwilling or unable to disclose genetic risks to their family. The problem, however, is that confidentiality is concerned with the security of personal information and the preservation of professional relationships. It cannot recognise claims by family members who have suffered harm following the nondisclosure of treatable genetic risks. A further issue is that although the proband is encouraged to ‘involve other family members in discussions about ... testing’<sup>27</sup> and, generally, patients are ‘keen to pass on information ... to relatives’,<sup>28</sup> it cannot be presumed that genetic information is shared automatically, for ‘geographical, social and emotional factors can mean that communication does not happen.’<sup>29</sup> The duty of confidentiality therefore offers no guarantee that clinicians will pick up the baton in these circumstances and make a disclosure. It is also significant that the uptake of genetic testing among blood relations doubles when a healthcare practitioner makes a disclosure as opposed to when a patient is relied on as a conduit of information about inherited risks. Disclosure by practitioners therefore has a significant positive impact on relatives’ access to preemptive therapies.<sup>30</sup>

### *Patterns of Inheritance*

Prior to engaging in substantive analysis, it is necessary to briefly outline some of the basic concepts of human genetics, particularly the different patterns of inheritance associated with genetic disorders. Genes, as has already been stated, are the fundamental unit of heredity and code proteins that enable organisms to function. The majority of cells in the human body contain 46 pairs of chromosomes and each pair contains two copies of any one gene (with the exception of the X and Y chromosomal pair). These are called diploid cells. Reproductive cells – gametes – only contain 23 single chromosomes and are haploid cells. At the point of conception, the haploid gametes merge to create a

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<sup>26</sup> *Attorney General v Guardian Newspapers (No. 2)* [1990] 1 AC 109.

<sup>27</sup> BMA, above, n 20, p. 315.

<sup>28</sup> Lucassen, A., and Parker, M., ‘Confidentiality and Sharing Genetic Information with Relatives’ *The Lancet* vol. 375, 1 May 2010, p. 1507.

<sup>29</sup> *Ibid.*

<sup>30</sup> Suthers, G.K., Armstrong, J., McCormack, J., and Trott, D., ‘Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder’ (2006) *J Med Genet* 43, 665–670

diploid cell called a zygote, which, through a process of cell division, becomes a foetus. The chromosomal pairs of the zygote are thus a combination of the 23 single chromosomes present in the reproductive cells of the parents. Each chromosome contains a complete sequence of DNA and each pair (with the exception of X and Y) has two copies of each gene.

Depending on the genome of the parents, a gene pairing inherited by a foetus may consist of 'two faulty copies, one faulty and one healthy copy, or two healthy copies' of a gene.<sup>31</sup> The recipient of 'two healthy copies of a particular gene will not suffer the disorder with which the gene is associated'.<sup>32</sup> The recipient of two faulty copies of a gene will, however, suffer the associated disorder subject to the degree of penetrance of that disorder.<sup>33</sup> An individual who has both a healthy and faulty copy of a gene may manifest the associated disorder depending on that disorder's pattern of inheritance. There are three common patterns of inheritance for monogenic – single gene – disorders: autosomal dominant, autosomal recessive and sex-linked. Alternately a condition can be polygenic or multifactorial – the result of the interaction of several genes and environmental factors.

*Autosomal Dominant:* these disorders – for example, Huntington's disease – require the presence of only one copy of a faulty gene. The faulty gene in the pairing asserts 'dominance' regardless of the presence of a healthy copy. Whether or not the disorder will eventuate is, however, dictated by the degree of penetrance of the condition. A parent with an autosomal dominant disorder has a 50 per cent chance of passing the genetic trait onto their progeny or sharing the condition with blood relatives.

*Autosomal Recessive:* this type of disorder requires an individual to possess two faulty copies of the relevant gene and includes conditions such as cystic fibrosis. If there is a healthy copy of the relevant gene present in a pairing, then that gene asserts 'dominance', thus for progeny to be affected by autosomal recessive disorders both parents must be asymptomatic carriers at the minimum. Those with a 'recessive' condition have a 25 per cent chance of sharing the disorder with blood relatives and a 50 per cent chance that those relatives will be asymptomatic carriers of the faulty gene. Knowledge of 'recessive' disorders is likely to be most significant in respect of reproductive decision-making.

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<sup>31</sup> British Medical Association, *Human Genetics: Choice and Responsibility* (OUP: Oxford, 1998), p. 31.

<sup>32</sup> *Ibid.*

<sup>33</sup> 'Penetrance' is 'the extent to which a particular gene or set of genes is expressed in the phenotypes of individuals possessing it, measured by the proportion of carriers of the gene showing the characteristic phenotype.' *Shorter Oxford English Dictionary*, 5<sup>th</sup> ed. (OUP: Oxford, 2002).

*Sex-linked Disorders:* The sex chromosomes in humans are stylized as XX for female and XY for male. Sex-linked disorders are conditions where the deleterious gene is present in the X chromosome but not the Y chromosome. These disorders – e.g. Haemophilia and Duchenne’s Muscular Dystrophy – are typically recessive thus in the female XX pairing the healthy gene is ‘dominant’, with women being asymptomatic carriers in the majority of cases. The male XY chromosome pair, however, does not have a second copy of the faulty gene and for this reason males are always affected by sex-linked disorders when a faulty gene is present. An individual with a sex-linked disorder has a 25 per cent chance of sharing the condition with blood relatives and a 50 per cent chance that a female relative will be an asymptomatic carrier.

*Multifactorial Disorders:* Monogenic disorders are caused by a fault in a single gene or pair of genes but multifactorial – or polygenic – disorders are caused by faults on several genes, sometimes in combination with external factors such as an individual’s lifestyle or environmental pollutants. Heart disease, cancer and diabetes all have a genetic component but – unlike autosomal dominant or autosomal recessive disorders – possession of a deleterious genetic trait is not wholly determinative of whether a condition will eventuate. It is, however, indicative of the level of risk. For this reason genetic information concerning multifactorial disorders is not as predictive as information concerning monogenic conditions. Nevertheless there is utility in knowing of heightened risks of disease and the opportunity such knowledge affords to obtain screening, diagnosis and medical intervention. Breast cancer is a useful example of the utility of genetic information in the treatment of polygenic conditions. The average risk of breast cancer is approximately 12 per cent, however, if a woman has a mutation on either the BRCA1 or BRCA2 gene the risk is elevated to between 50 and 80 per cent. Knowledge of the risk presents a woman with a significant opportunity to seek preemptive treatments, with options ranging from preventative therapies<sup>34</sup> to surgical intervention.<sup>35</sup> Early diagnosis is crucial in the treatment of cancers and knowledge of genetic risks could be particularly beneficial in the treatment of cancers that are typically diagnosed late, such as pancreatic cancer.

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<sup>34</sup> For more details, see Cuzik, J., et al, ‘Preventative therapy for breast cancer: a consensus statement’ (2011) *The Lancet Oncology* vol. 12(5), 496-503.

<sup>35</sup> BBC News, ‘Should I have breast cancer gene test?’ 14 July 2011; BBC News, ‘Angelina Jolie has double mastectomy due to cancer gene’ 14 May 2013; Jolie, A., ‘My medical choice’ *New York Times* 14 May 2013, available at <http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html?smid=tw-share&r=1&> (accessed 31 May 2013).

### *The Benefits of Disclosure*

Disclosing the genetic information of the proband to their blood relatives has a number of potential benefits. Chief among them is that disclosing genetic information forewarns descendants of common gene pools of potentially shared genetic risks. Dissemination of this knowledge provides individuals with opportunity to access genetic testing and medical intervention that could lead to harm being avoided or minimised. For example, a woman could undergo a double mastectomy if she discovered she had a high risk of developing breast cancer.<sup>36</sup>

The ‘availability of a cure carries with it the certainty that disclosure can incontrovertibly avert harm.’<sup>37</sup> The availability of treatment – as opposed to a *cure* – also indicates that disclosure can minimise or avert harm where a risk is potentially shared. For example, individuals at high risk of particular cancers have been found to benefit from daily doses of aspirin, the research indicating that reduces the risk of the disease eventuating.<sup>38</sup> Where no treatment is available for a condition, the benefits of disclosing genetic risks are less certain, although evidence exists that both supports<sup>39</sup> and refutes<sup>40</sup> ‘the benefits of disclosure in facilitating preparedness.’<sup>41</sup> Significantly, the courts have demonstrated a reluctance to engender the disclosure of genetic information in absence of medical benefit.<sup>42</sup>

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<sup>36</sup> See above, n 31.

<sup>37</sup> Laurie, G.T., *Genetic Privacy: a challenge to medico-legal norms* (Cambridge University Press: Cambridge, 2002), p. 122.

<sup>38</sup> Chan, A., Cook, R., ‘Are we ready to recommend aspirin for cancer prevention?’ *The Lancet* vol. 379, Issue 9826, 1569-1571; BBC News, ‘Aspirin “may prevent skin cancer”’ 29 March 2012; BBC News, ‘Daily aspirin “prevents and possibly treats cancer”’ 21 March 2012.

<sup>39</sup> Tarini, B., *et al*, ‘Parents’ interest in Predictive Genetic Testing for their Children when a Disease has no Treatment’ (2012) *Pediatrics* 129(2), 290-298; Buxton, J., Pembrey, M., ‘The New Genetics: What the Public Wants to Know’ (1996) 4 *European Journal of Human Genetics (Suppl.)* 153; Hietala, M., *et al*, ‘Attitudes towards genetic testing among the general population and relatives of patients with a severe genetic disease: a survey from Finland’ (1995) 56 *American Journal of Human Genetics* 1493.

<sup>40</sup> Almqvist, E., *et al*, ‘A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalisation after predictive testing for Huntington’s disease’ (1999) 64 *American Journal of Human Genetics* 1293; Almqvist, E., *et al*, ‘Risk of Reversal in Predictive Testing for Huntington’s Disease’ (1997) 61 *American Journal of Human Genetics* 945; Wexler, N., ‘Genetic Jeopardy and the New Clairvoyance’ (1985) 6 *Progress in Medical Genetics* 227.

<sup>41</sup> Laurie, above, n 34, p. 123.

<sup>42</sup> *Re YZ* [2013] EWHC Fam 935.

Gene therapy is another dimension to the argument in favour of disclosing genetic information. Somatic gene therapy involves inserting genetic material into the patient's genome to remedy a defect in their genes.<sup>43</sup> Deleterious genetic traits may therefore be corrected before the associated phenotype manifests. China was the first country to officially sanction gene therapy<sup>44</sup> and the European Medicines Agency recently recommended the European Commission approve gene therapy for lipoprotein lipase deficiency, with market authorisation being granted by the Commission in November 2012.<sup>45</sup> Promising results have been highlighted in the news,<sup>46</sup> however, the majority of clinical trials – 60.2 per cent – are in phase I, with 18.6 per cent between phases I and II and 21 per cent at phases II through IV.<sup>47</sup> Widespread clinical use is therefore some years away, however, developments in gene therapy are 'beginning to result in real clinical promise'.<sup>48</sup> As more gene therapies become available it will be possible to treat increasing numbers of genetic conditions at a pre-symptomatic stage. The benefits of disclosing genetic information in such circumstances are self-evident.

The benefits of disclosing genetic information may also extend beyond blood relatives. It is possible that healthcare providers could benefit economically. Pharmacogenomics could create the opportunity for a more efficient and medically effective distribution of medication and genetic testing could potentially increase access to cost saving, preemptive interventions. Cancer again provides an illustration: the estimated

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<sup>43</sup> This is to be contrasted with germ-line gene therapy, which involves insertion of genetic material into the pre-embryo or an individual's germ cells; the objective here is to correct a defect or remove a trait in the patient's progeny. This form of gene therapy is not without moral and ethical controversy. For an excellent summary, see Mason, J.K., Laurie, G.T., *Mason & McCall-Smith's Law and Medical Ethics*, 8<sup>th</sup> ed. (OUP: Oxford, 2011), pp. 243-246.

<sup>44</sup> Pearson, S., Jia, H., Kandachi, K., 'China approves first gene therapy' (2004) *Nature Biotechnology* 22, 3-4.

<sup>45</sup> See above, n 1.

<sup>46</sup> BBC News, 'Gene therapy gave me back sight' 8 February 2012; BBC News, 'Haemophilia gene therapy shows early success' 11 December 2011; BBC News, 'Gene linked to depression "fixed" in mice' 20 October 2010; BBC News, 'Gene therapy for blood disorder a "success"' 15 September 2010; BBC News, "'Seek and destroy" cancer gene therapy result hailed' 21 April 2010.

<sup>47</sup> See <http://www.abedia.com/wiley/phases.php>, the Gene Therapy Clinical Trials Worldwide website, provided by the Journal of Gene Medicine.

<sup>48</sup> Professor Norman Nevin, Gene Therapy Advisory Committee, Eleventh Annual Report (2004), p. 9.

cost of treatment in the UK in 2010 was £9.4 billion.<sup>49</sup> Suppose that prescribing aspirin to those individuals at risk of developing cancer resulted in a 25 per cent decrease of incidences of the disease – such a reduction equates financially to a potential saving of approximately £2.35 billion. Although healthcare providers would face an increase in expenditure for the preventative drug – in this basic hypothetical, aspirin – this would be offset by a reduced demand for chemotherapy, surgery and palliative care. A preemptive approach to disease could also facilitate a new method of resource allocation – for example, the availability of new cancer drugs could be increased for individuals who go on to develop the disease.

The hypothetical presented here is not definitive – it does not, for example, account for the cost of genetic testing or disclosure, both necessary considerations in any assessment of the economic benefits of disclosing genetic information – but it is not meant to be, instead it is an indication of the potential benefits disclosure may hold for healthcare providers. The focus of this thesis is on blood relatives and potential tortious claims when genetic information is not disclosed, however, it is important to note that healthcare providers are significant stakeholders in genetic medicine. It is therefore suggested that the potential economic benefits of disclosure warrant research.

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<sup>49</sup> BUPA, *Cancer Diagnosis and Treatment: a 2021 projection* (2011), available at [http://www.bupa.com/media/354684/cancer\\_diagnosis\\_and\\_treatment - a 2021 projection - final.pdf](http://www.bupa.com/media/354684/cancer_diagnosis_and_treatment_-_a_2021_projection_-_final.pdf). The figure incorporates the NHS, private and voluntary sectors.

## **2. Genetic Information and Data Sharing**

### *A Challenge to Confidentiality and Data Protection*

Genetic sequencing is becoming increasingly affordable and transitioning from laboratory setting to mainstream healthcare. Indeed, ‘straight-to-consumer’ testing is available for a price via the Internet.<sup>1</sup> Genetic information is therefore becoming increasingly available and greater access to this type of knowledge will challenge existing paradigms of confidentiality and data protection.

Medico-personal data has traditionally been ‘regarded as falling into the sphere of privacy, protected by both data protection laws and the professional obligation of confidentiality ... because it usually only concerns no one but the patient him- or herself.’<sup>2</sup> However, ‘the familial nature of genetic information’<sup>3</sup> challenges the established paradigm because genetic information simultaneously reveals information about the patient and their blood relations. Consequentially, a patient’s genetic information has utility for the individual and their family: specifically disclosure to blood relatives can facilitate access to screening and preemptive medical intervention. Though an argument can be made that genetic information is personal, demanding equivalent protection to other types of medico-personal data (which are considered ‘obviously private’<sup>4</sup> and ‘entitled to be protected by an obligation of confidence’<sup>5</sup>) the familial aspect of genetic information is difficult to adequately reconcile with an individualistic approach to confidentiality and data protection.

Descendants of a common gene pool ‘share’ genes, thus it is inevitable that clinicians engaged with genetic testing will find themselves in possession of information relevant to persons who are not their immediate patients. The significant question is whether sufficient justification exists for disclosing genetic information beyond the doctor-patient relationship.

It is argued here that a strict adherence to doctor-patient confidentiality and data protection will be undesirable in circumstances where disclosure provides a tangible

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<sup>1</sup> For example, 23andMe ([www.23andMe.com](http://www.23andMe.com)), which has recently struck problems in America – see BBC News, ‘FDA bans personal genetic tests’, 26 November 2013.

<sup>2</sup> McClean, S., *Autonomy, Consent and the Law* (Routledge-Cavendish: London, 2010) p. 155.

<sup>3</sup> *Ibid.*

<sup>4</sup> *Campbell v Mirror Group News* [2004] 2 AC 457, *per* Lord Hope at 95.

<sup>5</sup> *Ibid.*

benefit. By way of example, consider the following: a patient submits for genetic testing and it is established that she is genetically predisposed to bowel or breast cancer. Following diagnosis, the proband can undertake preventative therapies, which can reduce the risk of the disease eventuating.<sup>6</sup> In these circumstances, it is axiomatic that the proband's blood relations also stand to benefit from knowledge of her greater risk of developing cancer, since family members who share the risk are also able to seek preventative treatment. If the proband's doctor were to strictly adhere to confidentiality in these circumstances, blood relations would be denied access to preventative therapies and thus would face an increased risk of developing the condition.

This thesis argues that a duty to disclose genetic information is appropriate in such circumstances. Principles of confidentiality and data protection are not absolute, meaning it is possible for healthcare practitioners to disclose genetic information when justifiable. The problem is the current legal framework cannot recognise harm to individuals other than the data subject or confider. Thus if the proband's blood relations suffered harm because genetic information was not disclosed, no means of redress is currently available. That is not to say that confidentiality and data protection are dispensed with – quite the contrary. If a duty to disclose is to be sustainable then disclosure of genetic information must constitute an acceptable departure from the prevailing legal framework. The public interest has an important role to play in this regard as confidential information can be disclosed providing the disclosure is in the public interest.<sup>7</sup> Thus for a duty to disclose to constitute a legitimate infringement of confidentiality and data protection, it must be in the public interest to disclose genetic information to blood relatives. An important precursor to establishing a duty to disclose is therefore to establish what public interest favours disclosure of genetic information.

The purpose of this chapter is to provide an answer to the question 'what public interest might favour the disclosure of genetic information'. It will also outline why a duty to disclose is necessary should disclosure be in the public interest. To this end, the chapter is divided into four parts. Part one provides background on the different arguments that have been put forward regarding the confidentiality of genetic information. Part two sets

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<sup>6</sup> For example, see BBC News 'Aspirin helps protect against bowel cancer' 22 October 2010; BBC News 'Small Daily aspirin does "cuts cancer risk"' 7 December 2010; BBC News 'Breast cancer prevention drugs should be proscribed' 28 March 2011; BBC News 'Daily aspirin blocks bowel cancer' 28 October 2011; BBC News 'Aspirin and cancer prevention' 28 October 2011. See also Rothwell, P., *et al*, 'Effect of daily aspirin on long-term risk of death due to cancer: analysis of individual patient data from randomised trials' *The Lancet*, volume 377, Issue 9759, 1 January 2011.

<sup>7</sup> It should be added that disclosure in these instances is in absence of consent from the patient. If the patient consents to disclosure, the disclosure is uncontroversial.



out the specific context, exploring the key components of the legal and professional framework that governs medical information. Part three attempts to define a public interest that supports disclosure of genetic information. Finally, part four outlines why a duty to disclose is necessary even if a public interest justification exists within the current legal paradigm.

*Part I: Setting the Context (i) – Genetic Information and Confidentiality*

Confidentiality has long been ‘one of the cornerstones’<sup>8</sup> of the doctor-patient relationship as ‘few would go to those who were unable or unwilling to keep a patient’s intimate details to themselves.’<sup>9</sup> In *Hunter v Mann*, the court summarised a clinician’s legal obligation as:

‘the doctor is under a duty not to disclose, without the consent of the patient, information which he, the doctor, has gained in his professional capacity.’<sup>10</sup>

Confidentiality is not, however, a strictly legal sphere. The common law duty owes much to its counterpart ethical obligation, the origins of which can be traced back to the Hippocratic Oath, which required healthcare practitioners to keep secret ‘[a]ll that may come to my knowledge in the exercise of [their] profession ... which ought not to be spread abroad’. The modern ethical basis of the obligation is the Declaration of Geneva, which similarly requires practitioners to ‘respect the secrets confided in [them], even after the patient has died’. The legal obligation is based upon a public interest in maintaining confidences and it has been said that without respect for confidentiality ‘doctors will be discredited ... for future patients will not come forward if doctors are going to squeal on them’.<sup>11</sup> However, confidentiality is not an absolute concept and a breach of the obligation is justifiable when there exists a ‘countervailing public interest which favours disclosure’.<sup>12</sup>

The scope of the confidentiality – and, indeed, data protection – is an important consideration, since it is inevitable that a duty to blood relations will conflict with a

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<sup>8</sup> Laurie, G.T., ‘Obligations arising from Genetic Information – Negligence and the protection of Familial Interests’ [1999] CFLQ 109.

<sup>9</sup> Pattinson, S., *Medical Law and Ethics*, 3<sup>rd</sup> ed. (Sweet & Maxwell: London, 2011), p. 201.

<sup>10</sup> [1974] 2 All ER 414 *per* Boreham J at 417.

<sup>11</sup> *X v Y & Others* [1988] RPC 379 *per* Rose J at 386. See also *R (on the application of Axon) v Secretary of State for Health* [2006] QB 539 *per* Silber J at 563.

<sup>12</sup> *Attorney General v Guardian Newspapers* (No. 2) [1990] 1 AC 109, HL, *per* Lord Goff at 392.

doctor's obligations to their patients. Tensions between proband and family have not arisen so far because medical information has typically been 'regarded as falling to the sphere of privacy ... because it usually only concerns no one but the patient him- or herself.'<sup>13</sup> Genetic information, however, will simultaneously provide information about the individual and their family and this duality gives rise to legal and ethical tensions. These tensions have been the subject of a long running debate among commentators and opinion is divided about the most appropriate solution. There are three predominant schools of thought in the literature. These are best described as absolute confidentiality, a familial treatment of genetic information and a patient oriented approach. These divergent approaches will be considered in turn.

### *Absolute Confidentiality*

One possible approach to potential tensions between disclosure and confidentiality is to treat genetic information as strictly confidential, unless the proband consents to its disclosure. This is a conservative approach and prioritises the patient's interests in confidentiality and controlling their personal information, at the expense of potential benefits to family members who may share the proband's deleterious genetic traits. The House of Lords Select Committee on Science and Technology recommended this approach in its 1995 publication, *Human Genetics: The Science and the Consequences*, contending that unless the patient is willing to share their genetic information with relatives, the doctor should consider the confidence of their patient as paramount.<sup>14</sup> The Select Committee argued that nondisclosure placed the proband's family 'at no worse position than if no test had been performed' and, furthermore, '[t]o fail to respect the privacy of genetic information in this way could discourage couples from ... seeking information which could help them safeguard their health.'<sup>15</sup> A comparably robust approach to genetic information has been advocated by the French National Ethics Committee,<sup>16</sup> the

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<sup>13</sup> McClean, above, n 2, p. 155.

<sup>14</sup> House of Commons Select Committee on Science and Technology, Third Report 1994-1995, *Human Genetics: The Science and the Consequences* (HMSO: London, 1995).

<sup>15</sup> *Ibid.*, paragraphs 227-228.

<sup>16</sup> Comité Consultatif National d'Éthique pour les Sciences de la vie et de la Santé, No. 025 *Avis sur l'application des tests génétiques aux Études individuelles, Études familiales et Études de population. (Problèmes des 'banques de sang', des 'banques' de cellules et de l'informatisation des données)*. 24<sup>th</sup> June 1991.

Norwegian Ministry of Health and Social Affairs<sup>17</sup> and the Swiss Academy of Medical Sciences,<sup>18</sup> who were of the opinion that:

‘For results obtained in the course of genetic investigations, the same regulations governing professional medical secrecy and data protection apply as for other medical data. The medical doctor may make the medico-genetic findings available to third parties only with the consent of the person investigated or of his legal representative, and only after the implication of such disclosure have been explained to them.’<sup>19</sup>

The difficulty with an approach of absolute confidentiality – particularly when the premise is that put forward by the Select Committee on Science and Technology – is that once the proband has undergone testing, the position of the family is not analogous to when no test has been conducted. Once the patient’s genome is screened and the results returned, healthcare practitioners are in possession of information that simultaneously reveals data about the genetic heritage of the proband and their family. If information about genetic diseases is kept from the patient’s blood relations – when there is a therapeutic response available – there is a risk of harm.

Returning to the example of a patient with a genetic predisposition to cancer, it was observed that disclosure of the risk enables access to preventative therapies. If the deleterious trait identified concerns a condition that is typically diagnosed late, the information will be vital in achieving prompt, effective intervention. Pancreatic cancer provides a star illustration here: 90 per cent of cases are diagnosed too late in the pathological process to be operable and only three per cent of patients survive beyond five years. Knowledge of the deleterious trait is therefore beneficial because of the difficulties in diagnosing the condition. Disclosure of the information means blood relations also benefit from the prospect of earlier diagnosis and treatment, thus a potential exists for harm

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<sup>17</sup> Norway Ministry of Health and Social Affairs, *Biotechnology related to Human Beings* (Oslo, Norway, 1994).

<sup>18</sup> Swiss Academy of Medical Sciences, *Medical-Ethical Guidelines for Genetic Investigations in Humans* (1993) Bull Med Suisses 74 (No. 38) 1454.

<sup>19</sup> *Ibid.*, p. 6, guideline 3.7. The guideline is consistent with Article 321 of the Swiss Penal Code, which states: ‘1. Any person who in his capacity as a member of the clergy, lawyer ... doctor, dentist, pharmacist, midwife or as an auxiliary to any of the foregoing persons discloses confidential information that has been confided to him in his professional capacity or which has come to his knowledge in the practice of his profession shall be liable [for breach of confidentiality] ... 2. No offence is committed if the person disclosing the information does so with the consent of the person to whom the information pertains’.

to be avoided or minimised. In contrast, when the proband does not undergo screening and deleterious traits are unknown, disclosure does not offer the possibility of averting or minimising harm. The circumstances are not analogous. When a person undergoes screening, the healthcare practitioner is furnished with information concerning the long-term health of the individual and, simultaneously, their family. Thus they have knowledge of relatives' prospective genetic risks. When the proband has not been screened there is simply no information available.

An approach based upon absolute confidentiality has, however, achieved relatively little success, a notable exception being the Human Genetic Examination Act (HGE) in Germany.<sup>20</sup> Those institutions that previously advocated strong approaches to the confidentiality of genetic information have gradually altered their views as knowledge and understanding of the human genome and its role in disease has developed. It is perhaps telling that, with the exception of the HGE, the literature cited was published in the formative years of the Human Genome Project, suggesting that early discussions concerning genetic information and confidentiality focused upon protecting the individual's privacy, eschewing the difficulties posed by the (at the time, lesser understood) familial nature of genetics.<sup>21</sup> An interesting comparison will be how domestic law develops in respect of genetic information in light of the approach adopted by Germany.

#### *A Familial Approach*

A contrasting approach to the tensions between doctor-patient confidentiality and disclosure is to treat genetic information as belonging to the family as opposed to the individual patient. Parker and Lucassen suggest that when dealing with genetic information it is appropriate to switch from a 'personal model account' to a 'joint model account' explaining that while 'on the personal account model the default position is an assumption of confidentiality, on the joint account model it is assumed that information should be available to all account holders unless there are good reasons to do otherwise.'<sup>22</sup> Knoppers likewise argues that 'genetic information is necessarily familial and the needs

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<sup>20</sup> 374/09, 24<sup>th</sup> April 2009. See, in particular, s11.

<sup>21</sup> Knoppers has also recognised 'a gradual move away from the status quo position of absolute confidentiality, to an intermediary position of it being the duty of the patient, [and then] to a position making it ethically permissible for the physician to warn in certain limited circumstances.' Knoppers, B.M., 'Genetic Information and the Family: are we our brother's keeper?' (2002) *Trends Biotechnol* 20, 85-86.

<sup>22</sup> Parker, M., Lucassen, A., 'Genetic Information: A Joint Account?' (2004) *BMJ* 329 165-167, p. 166.

and interests of other family members cannot be ignored',<sup>23</sup> and Gilbar goes as far as suggesting that '[w]hen familial tensions over genetic information arise ... the strict rule of confidentiality should be relaxed and provide room for the ethics of the family.'<sup>24</sup>

The familial approach is based upon the presumption that '[g]enetic information is, spontaneous mutations aside, unavoidably familial in nature.'<sup>25</sup> Genes are the fundamental unit of hereditary and individuals descended from a common gene pool 'share' genetic heritage. Thus deleterious traits identified in the proband's genome may also be present in the genome of blood relations. However, a familial model of genetic inheritance is not without critics and Liao argues against any portrayal of genes as being unequivocally familial because 'depending on the disease, spontaneous mutations occur frequently.'<sup>26</sup> Liao contests that genetic disorders are not necessarily the product of an inherited trait and can instead occur as a result of a spontaneous mutation within an individual's genome post-conception. There are studies that lend some weight to his argument, for example, it has been identified that 33 per cent of cases of Duchenne's muscular dystrophy (DMD) are the result of a spontaneous mutation and not the individual's biological inheritance. But while the figure is substantial the remaining 67 per cent of cases are a consequence of an inherited trait and – although a third of cases will not be the result of family genetics – a significant chance remains that the deleterious gene has been inherited. In the case of DMD, this means that there is a two in three chance it is a familial gene and other members of the proband's family are at risk of passing the disorder on to their progeny.

For this reason it is difficult to exclude the possibility that deleterious genetic traits are shared by the proband's family. Although some instances of a disease will occur as the result of spontaneous genetic mutations, it is only possible to rule out inheritance by screening a patient's close relatives for that genetic trait. Unless there exists compelling evidence to the contrary, the presumption that '[g]enetic information is ... unavoidably familial in nature' is an irresistible perspective.

The difficulty with pursuing a familial approach or joint account model is, however, the palpable gap between genetic disorders that can be identified through screening and those for which a therapeutic response is available. As Mason and Laurie explain '[access to] genetic information does not necessarily allow us to avoid genetic

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<sup>23</sup> Knoppers, above, n 21.

<sup>24</sup> Gilbar, R., 'Communicating Genetic Information in the Family: the familial relationship as the forgotten factor' (2007) *J Med Ethics* 33, 390-393.

<sup>25</sup> Parker, Lucassen, above, n 22, p. 166.

<sup>26</sup> Liao, S., 'Is there a Duty to share Genetic Information?' (2009) *J Med Ethics* 35, 306-309.

disease.’<sup>27</sup> The benefits of universal disclosure are therefore drawn into question, for although

‘availability of a cure carries with it the certainty that disclosure can incontrovertibly avoid harm ... few cures or minimally invasive therapies are currently available for genetic conditions. And if disclosure is made to avoid an ancillary harm such as psychological upset there is less of a guarantee that the harm in question will, de facto, be avoided.’<sup>28</sup>

Until a greater number of therapeutic responses are available for genetic disorders, a joint account model may be difficult to argue as a realistic preference when dealing with genetic information. One counterpoint may be that as more information enters the public domain through disclosure, the chances of a greater number of therapeutic responses increase as knowledge accrues. Thus a joint account model may coincide with a general public interest argument in terms of the benefit of sharing sensitive and confidential medical information.<sup>29</sup> However, whether or not a familial approach is presently achievable, the shared nature of our genetic heritage remains an important dimension to the debate on disclosing genetic information. It is a dimension that should not be ignored.

#### *A Patient Oriented Approach*

The final approach to the tension between the familial aspect of genetics and doctor-patient confidentiality constitutes the prevalent approach to confidentiality in the UK. The common law duty is based on ‘a public interest that confidences should be preserved’.<sup>30</sup> However, the obligation is not absolute and breaching it can be justified when the public interest in confidentiality is ‘outweighed by some other countervailing public interest which favours disclosure’.<sup>31</sup> The legal position is reflected in the self-regulatory framework of the medical professions. The GMC’s 2009 guidelines on confidentiality explain that a patient’s medical information may be disclosed without consent where a

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<sup>27</sup> Mason, J.K., Laurie, G.T., *Mason & McCall-Smith’s Medical Law and Ethics*, 9<sup>th</sup> ed. (OUP, Oxford: 2013) p. 220.

<sup>28</sup> Laurie, above, n 8, p. 122.

<sup>29</sup> An altruistic approach to sharing genetic information for general benefit and medical development is a point to which we return in Part III.

<sup>30</sup> *Guardian Newspapers*, above, n 12, per Lord Goff at 282.

<sup>31</sup> *Ibid.*

‘failure to disclose may expose others to risk of death or serious harm.’<sup>32</sup> The guidelines expressly address genetic information but provide little meaningful content, merely stating that healthcare practitioners should balance their duty of care to the patient against their duty to help protect others from serious harm, leaving much to the discretion of the individual clinician.<sup>33</sup> The British Medical Association (BMA) provides similarly broad advice in the context of genetics, stating that ‘the doctor’s duty of confidentiality to the individual patient is of fundamental importance and should be breached only when there is a legal requirement or overriding public interest.’<sup>34</sup> This raises the question: what constitutes an overriding public interest in the genetic context?<sup>35</sup>

A patient oriented approach to confidentiality and genetic information also draws support from the Nuffield Council on Bioethics who in their 1993 publication, *Genetic Screening: ethical issues*, assessed possible tensions between doctor-patient confidentiality and the interests of other family members in genetic information. The council reflected the position expressed by Rose J in *X v Y*,<sup>36</sup> stating:

‘Respect for privacy is vital to the doctor/patient relationship. The relationship is one which must be built on trust and confidence if the patients are to reveal information essential to the proper diagnosis and treatment of their condition. Yet trust and confidence would be shattered if doctors were to fail to respect the confidentiality of intimate personal information.’<sup>37</sup>

While the council acknowledged that ‘the accepted standards of the confidentiality of medical information should be followed as far as possible’,<sup>38</sup> they also accepted that ‘in exceptional circumstances, health professionals might be justified in disclosing genetic information to other family members, despite an individual’s desire for confidentiality.’<sup>39</sup>

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<sup>32</sup> General Medical Council, *Confidentiality: guidelines for doctors* (London, 2009), paragraph 53.

<sup>33</sup> *Ibid.*, paragraph 69.

<sup>34</sup> British Medical Association Ethics Department, *Medical Ethics Today: the BMA’s handbook of ethics and law*, 2<sup>nd</sup> ed. (BMJ Books: London, 2004), p. 315.

<sup>35</sup> This question is considered in Part III below.

<sup>36</sup> [1988] RPC 379 at 386.

<sup>37</sup> Nuffield Council on Bioethics, *Genetic Screening: ethical issues* (London, 1994), at 5.10.

<sup>38</sup> *Ibid.*, at 5.7(i).

<sup>39</sup> *Ibid.*, at 5.7(iii).

The Human Genetics Commission (HGC) and the Department of Health have also endorsed a patient oriented approach to genetic information,<sup>40</sup> while at a regional level the European Convention of Human Rights and Biomedicine states that the proband's genetic risks may be disclosed in circumstances 'proscribed by law [that] are necessary in a democratic society in the interest of public safety ... the protection of public health or for the protection of the rights and freedoms of others.'<sup>41</sup>

A patient focused approach to confidentiality is also practiced in non-EU countries, notably Switzerland. The approach is a significant deviation from the opinion advanced by the Swiss Academy of Medical Sciences and is incorporated in Art 119f of the Swiss constitution, which states that a 'person's genetic material may only be analysed, registered or disclosed with consent or if the law so provides'.<sup>42</sup> At an international echelon, support for a patient focused approach comes from the United Nations Economic, Scientific and Cultural Organisation (UNESCO) whose Universal Declaration on Bioethics and Human Rights states:

'The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law.'<sup>43</sup>

UNESCO's preference for a patient oriented approach when dealing with the possibly conflicting interests of the proband and members of their family is further emphasised by the International Declaration on Human Genetic Data, which reads:

'Human genetic data ... should not be disclosed or made accessible to third parties, in particular, employers, insurance companies, educational institutions and the *family*, except for an *important public interest reason* in cases restrictively

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<sup>40</sup> Human Genetics Commission, *Inside Information: balancing interests in the use of personal genetic data* (HMSO: London, 2002), paragraph 3.62; *NHS Code of Practice: Confidentiality* (Department of Health: London, 2003), Annex B, paragraph 30.

<sup>41</sup> European Convention on Human Rights and Biomedicine (1997) Art 26(1).

<sup>42</sup> Constitution of Switzerland (1999). English language version (amended as of 8<sup>th</sup> February 2011) available at <http://www.servat.unibe.ch/icl/sz00000.html>.

<sup>43</sup> UNESCO Universal Declaration on Bioethics and Human Rights Art 9.



provided for by domestic law consistent with the international law of human rights.’<sup>44</sup>

UNESCO’s position is arguably consistent with the current domestic approach to confidentiality, permitting doctor-patient confidentiality to be justifiably breached where there exists a countervailing interest favouring disclosure. It is clear that both UNESCO and the GMC accept that exceptions to confidentiality are necessary in the genetic context but generally expect healthcare practitioners to place the interests of the patient ahead of those of their family. However, there is a paucity of case law on what constitutes a countervailing public interest in respect of disclosing genetic risks. Professional guidance has not indicated in what circumstances it may be appropriate to disclose either, the decision making process thus far being left to clinical judgement. In the first instance, the proband is relied upon to disclose genetic information to their relatives, which, as previously indicated, is not certain to happen.

#### *Part II: Setting the Context (ii) – The Legal Framework*

The legal framework governing the privacy of medical information is a tapestry of common law and statutory provisions. The core elements with which this thesis is concerned are the common law obligation of confidentiality and the Data Protection Act 1998 (DPA), which implements a 1995 EC Directive. This common law and statutory framework exists against a backdrop of human rights instruments, thus the European Convention on Human Rights (ECHR) – largely transposed into domestic law by the Human Rights Act 1998 (HRA) – must also be taken account of. There are other provisions to which healthcare practitioners are also subject,<sup>45</sup> but analysis of these is beyond the scope of this chapter.

It is the aim here to outline the legal framework and set the regulatory context for the question addressed in part three of this chapter: namely, what public interest might favour the disclosure of genetic information to the proband’s blood relations?

#### *The European Convention on Human Rights*

The ECHR is a backdrop for many regulatory frameworks and the privacy of medical information is no exception. Convention rights are intimately bound up in issues of data protection and confidentiality, with the critical provision in this context being Art 8 – the

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<sup>44</sup> UNESCO International Declaration on Human Genetic Data Art 14(b).

<sup>45</sup> I.e. the Health Service (Control of Patient Information) Regulations 2002.

right to respect for private and family life – which is incorporated into domestic law by the HRA.<sup>46</sup> Art 8(1) states ‘[e]veryone has the right to respect for his private and family life, his home and his correspondence’ and medico-personal data falls within its scope.<sup>47</sup> It is important to note, however, that although Convention rights are engaged by the regulation of medico-personal data there is currently no freestanding action for breach of privacy in the UK. Under the terms of the HRA public authorities must act compatibly with convention rights, s6(1) stating ‘[i]t is unlawful for a public authority to act in a way which is incompatible with a Convention right’. Actions for breach of privacy can therefore be brought under this umbrella duty when the defendant is a public body, such as the National Health Service. Where the State – through its authorities – fails to respect Convention rights, it too can be subject to a claim in the European Court of Human Rights in Strasbourg. When a breach of Art 8 does not involve a body of the State, claims are generally articulated through confidentiality, misuse of private information and defamation.

The right to respect for private life is a qualified right. Art 8(2) defines the scope of the right, explaining that interference with the right to privacy by a public authority is only acceptable when it is

‘in accordance with the law and ... necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.’

Since issues of data protection and confidentiality will engage Art 8, any exceptions to medical secrecy must be consistent with at least one of the limitations in Art 8(2) ECHR. These restrictions are broad and encapsulate matters of public interest, the margin of appreciation leaving a degree of interpretation to individual States. Of particular relevance here is that privacy can be legitimately interfered with to protect health or the rights and freedoms of others, and, arguably, disclosing genetic information might be justified under either. Thus the significant question is whether there exists a compelling public interest justification for breaching data protection and confidentiality. If it is in the public interest to disclose, then it appears that the broad restrictions in Art 8(2) could be satisfied and the proband’s Convention rights legitimately infringed.

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<sup>46</sup> s1(1) Human Rights Act 1998

<sup>47</sup> *Z v Finland* (1997) Application no. 22009/93; *Cornelius v De Taranto* [2001] EWCA 1511.

### *Confidentiality*

The obligation to maintain confidentiality ‘arises when confidential information comes to the knowledge of a person ... in circumstances where he has notice, or is held to have agreed, that the information is confidential’.<sup>48</sup> It will be held that an individual agreed the information was confidential when it is received in circumstances where the reasonable person ought to have known of its confidential status. The common law obligation applies to all confidential information and not merely medico-personal data, but it constitutes ‘one of the cornerstones’ of the doctor-patient relationship.<sup>49</sup>

The provision of medical treatment is strongly reliant on a relationship of trust between clinician and their patients, and the obligation of confidentiality is an important factor in developing the requisite degree of trust between the parties. As Rose J robustly emphasized in *X v Y & Others* ‘patients will not come forward if doctors are going to squeal on them’.<sup>50</sup> Commentators have likewise highlighted the essential role of confidentiality in developing a successful doctor-patient relationship because patients

‘need to believe that those whom they go to for medical advice, diagnosis and treatment are competent and discreet ... [and] few would go to those who were unable or unwilling to keep a patient’s intimate details to themselves.’<sup>51</sup>

The key function of confidentiality within the doctor-patient relationship is further emphasised by professional guidelines, the GMC stating

‘[w]ithout assurances about confidentiality, patients may be reluctant to seek medical attention or give doctors the information they need in order to provide good care.’<sup>52</sup>

The BMA likewise reiterates that confidentiality is crucial to successful medical care, observing that ‘[p]atients who do not believe that their secrets will be protected may

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<sup>48</sup> *Attorney General v Guardian Newspapers (No. 2)* [1990] 1 AC 09, per Lord Goff at 281.

<sup>49</sup> Laurie, G.T., ‘Obligations arising from Genetic Information – Negligence and the Protection of Familial Interests’ [1999] CFLQ 109.

<sup>50</sup> [1988] RPC 379 at 386.

<sup>51</sup> Pattinson, above, n 9, p. 201.

<sup>52</sup> General Medical Council, *Confidentiality: guidelines for doctors* (London, 2009), paragraph 6.

withhold information that is important not only to their health but possibly the wellbeing of others.’<sup>53</sup> This latter observation is particularly cogent with respect to genetic information. Although, in general, patients are ‘keen to pass on information ... to relatives’,<sup>54</sup> a situation might arise where a patient refuses to undergo screening because they do not believe that their genetic information will be sufficiently protected.<sup>55</sup>

The conceptual foundations of the clinical obligation to respect patients’ confidences are simultaneously drawn from medical ethics and law and, as Mason and Laurie explain, it is a context wherein ‘it is difficult to dissociate the two disciplines’.<sup>56</sup> The ethical content of doctor-patient confidentiality is a powerful influence on its legal form for, as Coleridge LJ articulated in *R v Instan*, ‘[a] legal common law duty is [often] nothing else than the enforcing by law of that which is a moral obligation without legal enforcement.’<sup>57</sup>

The ethical backbone of doctor-patient confidentiality can be traced to the Hippocratic Oath, which read ‘all that may come to my knowledge in the exercise of my profession ... which ought not to be spread abroad, I will keep secret and will never reveal.’ In *Hunter v Mann*,<sup>58</sup> Boreham J attributed a legal definition to the clinician’s obligation of confidentiality consistent with that ethical duty. He stated:

‘[a] doctor is under a duty not to disclose, without the consent of the patient, information which he, the doctor, has gained in his professional capacity.’<sup>59</sup>

His definition highlights the relationship between medical ethics and law when it comes to doctor-patient confidentiality. In the modern era, the ethical basis of the clinical obligation is the Declaration of Geneva, which requires medical practitioners to ‘respect the secrets

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<sup>53</sup> British Medical Association Ethics Department, *Medical Ethics Today: The BMA’s Handbook of Ethics and Law*, 2<sup>nd</sup> ed. (BMJ Books: London, 2004), p. 165.

<sup>54</sup> Lucassen, A., Parker, M., ‘Confidentiality and Sharing Genetic Information with Relatives’, *The Lancet*, vol. 375, 1 May 2010, p. 1057.

<sup>55</sup> An interesting question, but one which is beyond the scope of this thesis, is whether patients would, in general, distinguish between disclosures to family members for health reasons and disclosures to other interested parties such as employers or insurers when weighing up whether their genetic information would be sufficiently confidential.

<sup>56</sup> Mason, Laurie, 27, p. 173.

<sup>57</sup> [1893] 1 QB 450 at 453.

<sup>58</sup> [1974] QB 767

<sup>59</sup> *Ibid.*, at 772.

confided in [them]’. But, as Mason and Laurie observe ‘the word “respect” is open to interpretation’.<sup>60</sup> The flexibility inherent in the language of the Declaration is consistent with the legal and professional views expressed in the UK, which portray confidentiality as a crucial element in medical practice but one that ‘is not absolute’.<sup>61</sup>

Commentators have advanced various interpretations of the conceptual underpinnings of confidentiality, exploring the issue from both ethical and legal perspectives. Ethical justifications for respecting patient confidentiality have been suggested as flowing from principles of autonomy and utility,<sup>62</sup> while departure from the obligation in particular circumstances is supported by principles of non-maleficence and beneficence.<sup>63</sup> Commentary from a legal perspective, such as that of Libling, has suggested that the concepts underpinning confidentiality flow from property rights in information.<sup>64</sup> Others have proposed that the basis of an action for breach of confidence is in fact the ‘broad equitable principle of good faith’.<sup>65</sup> However, as Laurie explains, ‘one common and unifying source for the duty of confidentiality can be identified from the case law. That source is the public interest.’<sup>66</sup>

The public interest was central to the House of Lords decision to uphold confidentiality in *Attorney General v Guardian Newspapers (No. 2)*<sup>67</sup> and *Lord Advocate v Scotsman Publications*.<sup>68</sup> In *Guardian Newspapers* it was stated by Lord Keith that ‘as a

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<sup>60</sup> Mason, Laurie, above, n 27, p. 177.

<sup>61</sup> General Medical Council, *Confidentiality*, above, n 51, paragraph 8. Opinion 5.05 of the American Medical Association Code of Medical Ethics contains a comparable sentiment. It states that the ‘information disclosed to a physician by a patient should be held in confidence ... The physician should not reveal confidential information without the express consent of the patient, subject to certain exceptions which are ethically [or legally] justified because of overriding considerations.’

<sup>62</sup> Ngweni, C., Chadwick, R., ‘Genetic Diagnostic Information and the Duty of Confidentiality: ethics and law’ (1993) 1 *Medical Law International* 73; Gillon, R., ‘Medical Ethics: Four Principles plus Attention to Scope’ (1994) 309 *British Medical Journal* 184.

<sup>63</sup> Moodle, P., Wright, M., ‘Confidentiality, Codes and Courts: an examination of the significance of professional guidelines on medical ethics in determining the legal limits of confidentiality’ (2009) 29 *Anglo-American Law Review* 39.

<sup>64</sup> Libling, D.F., ‘The Concept of Property: Property in Intangibles’ (1978) 94 LQR 103.

<sup>65</sup> Jones, G., ‘Restitution of Benefit Obtained in Breach of Another’s Confidence’ (1970) 86 LQR 463 at p. 466.

<sup>66</sup> Laurie, G.T., *Genetic Privacy: a challenge to medico-legal norm* (Cambridge University Press: Cambridge, 2002), p. 18.

<sup>67</sup> [1990] 1 AC 109, HL.

<sup>68</sup> 1989 SLT 705, HL.

general principle it is in the public interest that confidences should be respected'.<sup>69</sup> Lord Goff agreed, stating 'there is such a public interest in the maintaining of confidences that the law will provide remedies for their protection.'<sup>70</sup>

In *Campbell v Mirror Group News*<sup>71</sup> the House of Lords opined that the language of breach of confidence had shifted from 'a balance of public interests to a balance of Article rights'.<sup>72</sup> However, the substance of confidentiality does not appear to have changed. Lord Hope, in particular, doubted the semantic evolution necessitated by the Human Rights Act fundamentally altered the centre of gravity of the action, explaining that 'the balancing exercise ... is essentially the same exercise, although it is plainly now more carefully focused and more penetrating.'<sup>73</sup> *Campbell* concerned an internationally recognised supermodel being covertly photographed attending a narcotics clinic after publicly stating she was not addicted to drugs. The claimant did not seek to prevent publication of her addiction but brought an action for breach of confidence concerning publication of additional details of her therapy and the photographs of her attending the clinic. The House of Lords was challenged with striking a balance between the claimant's Art 8 right to respect for privacy and the defendant's Art 10 right to freedom of expression. Despite articulating the balancing exercise as one between convention rights, the key concept remained the public interest, Lord Hoffmann explaining:

'While there is no contrary public interest recognised and protected by the law, the press is free to publish anything it likes. Subject to the law of defamation ... But when press freedom comes into conflict with another interest protected by the law, the question is whether there is a sufficient public interest in that particular publication to justify the curtailment of the conflicting right.'<sup>74</sup>

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<sup>69</sup> *Guardian Newspapers*, above, n 67, at 256.

<sup>70</sup> *Ibid.*, at 281.

<sup>71</sup> [2004] 2 AC 457.

<sup>72</sup> Mason, Laurie, above, n 27, p. 182.

<sup>73</sup> *Campbell*, above, n 71, at 86.

<sup>74</sup> *Ibid.*, at 56.

*Campbell* exemplifies the dicta of Lord Wilberforce in *British Steel Corporation v Granada Ltd*,<sup>75</sup> where he stated that there exists ‘a wide difference between what is interesting to the public and what is in the public interest.’<sup>76</sup> The House of Lords ultimately found in favour of the claimant: although publication to correct the previous inaccurate statements regarding the claimant’s addition was in the public interest, it was held that publishing additional details of her therapies and covertly taken photographs were not.

It is noteworthy that (although instructive regarding the continuing importance of public interests in breach of confidence) *Campbell* is distinct from cases concerning doctor-patient confidentiality because it did not involve a relationship giving rise to a *prima facie* obligation of confidence. Instead it involved circumstances where the claimant was entitled to a ‘reasonable expectation of privacy’.<sup>77</sup> Although there is overlap between Art 8 privacy and common law confidentiality it is crucial to recognise that the two concepts are not synonymous: confidentiality ‘is concerned as much with the protection of a relationship as with personal information’,<sup>78</sup> whereas privacy ‘requires no relationship and is concerned with the interest that encompass ... personal information’.<sup>79</sup>

The obligation of confidentiality is also subject of professional guidance and this guidance distills broad principles from the case law, providing healthcare practitioners with an indication of when it may be justifiable to breach confidentiality. The GMC, for example, explains that while confidential medical care is in the public interest ‘there can also be a public interest in disclosing information’ and this can arise

‘to protect individuals or society from risks of serious harm ... or to enable medical research, education or other secondary uses of information that will benefit society over time.’<sup>80</sup>

The guidance indicates that medico-personal data may be disclosed without patient consent provided ‘the benefits to an individual or to society of the disclosure outweigh both the

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<sup>75</sup> [1981] AC 1096.

<sup>76</sup> *Ibid.*, at 1168.

<sup>77</sup> *Campbell*, above, n 71, *per* Lord Nicholls at 21, Lord Hope at 96 and Baroness Hale at 134.

<sup>78</sup> Laurie, above, n 66, p. 211.

<sup>79</sup> *Ibid.*, p. 212.

<sup>80</sup> General Medical Council, *Confidentiality*, above, n 52, paragraph 36.

public and the patient's interest in keeping the information confidential.'<sup>81</sup> The GMC's guidelines are not a source of further detail of when a public interest may justify disclosure, but they do require healthcare practitioners to consider the patient's private interest in confidentiality – an irrelevant factor in a legal analysis of the justification for breach of confidence.<sup>82</sup> The GMC further requires doctors to weigh possible harms of nondisclosure against possible harm to the overall trust between doctors and patients.<sup>83</sup> The guidance also stipulates that the clinician must 'be satisfied that the identifiable information is necessary for the purpose'.<sup>84</sup> Doctors must therefore engage in a balancing exercise that takes account of additional factors to those considered by the courts, but the guidance available provides only a broad framework and much is left to clinical discretion.

The BMA likewise recognises that 'on occasion, the public interest may be seen to override the privacy of an individual' and explains that disclosure 'essential to prevent or lessen a serious and immediate threat to public health or to the life and health of another individual typifies this category of justification.'<sup>85</sup> These examples are, however, not treated as exhaustive and it is recognised that 'neat divisions are not entirely satisfactory and, in many cases, harm is multifaceted.'<sup>86</sup> Unlike the GMC, the BMA does not place particular emphasis on the patient's personal interest in confidentiality when reaching a just balance between competing interests, in fact recognising that a 'decision to disclose is often not based on the interests of the person concerned'.<sup>87</sup> It further encourages clinicians 'where feasible ... to try to envisage the seriousness of the potential harm from the viewpoint of the person likely to suffer it.'<sup>88</sup>

The justification for a legal obligation of confidentiality can thus be characterised as based upon a public interest in confidentiality. Significantly, breaching the obligation may also be justified by reference to a public interest. In the genetic context, a doctor may therefore be able to justify disclosing their patient's genetic information to blood relations if a countervailing interest favouring disclosure can be identified. This returns us to the

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<sup>81</sup> *Ibid.*

<sup>82</sup> *W v Egde* [1990] 1 All ER 835.

<sup>83</sup> General Medical Council, *Confidentiality* above, n 52, paragraph 37.

<sup>84</sup> *Ibid.*, paragraph 38.

<sup>85</sup> BMA, above, n 53, p. 189.

<sup>86</sup> *Ibid.*, p. 190.

<sup>87</sup> *Ibid.*

<sup>88</sup> *Ibid.*



central question – which receives a ‘frustratingly ill-defined’ reply<sup>89</sup> – what constitutes a countervailing interest justifying disclosure? This is a point to which this chapter returns in part three, below.

### *The Data Protection Act 1998*

The Data Protection Act 1998 (DPA), which implemented a 1995 European Directive, covers the processing of personal data and provides ‘further protection for medical information.’<sup>90</sup> Data protection law subdivides information into two categories: personal data and anonymised data. Both categories are relevant in the healthcare setting but anonymised data does not engage the provisions of the Data Protection Act. What in fact constitutes ‘anonymised’ data is, however, a source of contemporary debate.<sup>91</sup> The role of anonymisation in actions for breach of confidence is also contentious.<sup>92</sup>

Here the focus is on personal data. Within data protection context, personal data is defined as ‘any information relating to an identified or identifiable natural person’ and an identifiable person ‘is one who can be identified directly or indirectly, in particular by reference to mental, economic, cultural or social identity’.<sup>93</sup> Usually, information concerning an individual’s health will fall within the definition of personal data, but there are times when it is unclear that information is actually ‘personal’.<sup>94</sup> If the information is regarded as personal data, the DPA regulates the ‘processing’ of that data. The Directive attributed a wide definition to ‘processing’, the term including:

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<sup>89</sup> Mason, Laurie, above, n 27, p. 183.

<sup>90</sup> *Ibid.*, p. 187.

<sup>91</sup> See *Common Service Agency v Scottish Information Commissioner* [2008] UKHL 47, which concerned disclosure of incidences of childhood leukemia in the Dumfries and Galloway postal areas. For commentary see Laurie, G.T., Gertz, R., ‘The worst of all worlds? *Common Service Agency v Scottish Information Commissioner*’ (2009) 13 Edin LR 330.

<sup>92</sup> See *R v Department of Health ex parte Source Informatics* [2001] QB 424 (CA), also *Department of Health v Information Commissioner* [2011] EWHC 1430. For commentary see Beyleveld, D., Histed, E., ‘Anonymisation is not exoneration’ (1999) 4 Med L Internat 69 and ‘Betrayal of confidence in the Court of Appeal’ (2000) 4 Med L Internat 277.

<sup>93</sup> Data Protection Directive (1995), Art 2.

<sup>94</sup> E.g. *Department of Health v Information Commissioner* [2011] EWHC 1430 (Admin), which concerned a refusal by the Department of Health to publish a breakdown of conditions that had justified late terminations of pregnancy. The Department of Health argued that this was personal data because of the small number of terminations carried out post-24 weeks and could be used to identify potentially vulnerable women and healthcare practitioners who had carried out the abortions. Cranston J disagreed.

‘any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organisation, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction.’<sup>95</sup>

As Mason and Laurie note, ‘there is little that could be done with data which would not fall within such a definition’,<sup>96</sup> although there are exceptions.<sup>97</sup> Once it is established ‘personal data’ is being ‘processed’, the DPA seeks to regulate this processing by reference to eight principles defined in Schedule 1 of the act. These principles ensure that data is processed only when fair and lawful to do so, processed and kept only so far as is necessary for the purposes it was obtained, accurate and kept up to date, and not transferred to a jurisdiction with inadequate data protection provisions.

The processing of personal data will only be fair and lawful providing that, in conjunction with meeting obligations of confidentiality, at least one condition from Schedule 2 of the act is met.<sup>98</sup> Where processing involves sensitive personal data, which includes information about an individual’s ‘physical or mental health or condition’,<sup>99</sup> then at least one condition from both Schedule 2 and Schedule 3 must be satisfied.<sup>100</sup> Under Schedule 2, the data subject must give valid consent to the processing of their personal information or, alternately, processing must fall within one of six exceptions to the consent requirement – the most significant, in the context of genetic information, being Schedule 2, paragraph 5(d), under which processing can be justified if it is necessary ‘for the exercise of any ... functions of a public nature exercised in the public interest’. Schedule 3 contains ten exceptions to the requirement of explicit consent, the most relevant being paragraph 8(1), which states processing without consent is justifiable if it is ‘necessary for medical purposes’ and undertaken by a healthcare practitioner<sup>101</sup> or someone with an equivalent

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<sup>95</sup> Data Protection Directive, Art 2(b).

<sup>96</sup> Mason, Laurie, above, n 27, p. 188.

<sup>97</sup> E.g. *Johnson v Medical Defence Union Ltd* [2007] 3 CMLR 9.

<sup>98</sup> Data Protection Act 1998, Schedule 1, paragraph 1(a).

<sup>99</sup> s2(e) Data Protection Act 1998.

<sup>100</sup> Data Protection Act 1998, Schedule 1, paragraph 1(b).

<sup>101</sup> Paragraph 8(1)(a).

duty of confidentiality.<sup>102</sup> ‘Medical purposes’ are defined broadly in paragraph 8(2) and include ‘preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services.’ A further justification for processing personal data in absence of consent – and which is likely to be relevant in the context of genetics – is found in Schedule 3, paragraph 3(c), which states processing can be justified if necessary to ‘protect the vital interests of another person, in a case where consent on behalf of the data subject has been unreasonably withheld’. The exceptions contained in Schedule 3 may provide justification for disclosing genetic information to a patient’s blood relations – it could either be couched as preventative medicine or protecting the vital interests of another. However, it is important to remember that for these exceptions to the consent requirement to apply, one of the conditions in Schedule 2 must initially be satisfied. Paragraph 5(d) – ‘the exercise of any ... functions of a public nature exercised in the public interest’ – has been highlighted as being the most appropriate of the Schedule 2 conditions in the context of disclosing genetic information. This, in turn, returns us to the question posed in respect of confidentiality – what is the public interest that favours disclosure?

### *Part III: A Public Interest in Disclosure*

It is clear that for the disclosure of genetic information to be considered a justifiable departure from confidentiality and data protection – and, thus, the argument in favour of a duty to disclose sustainable – the disclosure must be in the public interest. Jurisprudence on medical confidentiality emphasises ‘the important public interest(s) served by respecting patient confidences’,<sup>103</sup> but the clinical obligation to protect patient’s secrets can be ‘outweighed by some other countervailing [public] interest which favours disclosure’.<sup>104</sup> Personal data can also be processed non-consensually under the terms of the DPA, provided such is necessary in the exercise of a function of a public nature, exercised in the public interest; the provision of healthcare foreseeably falling within the catch all term – ‘functions of public nature’ – employed here. The exception to confidentiality and the precondition for processing highlighted in the DPA are logically conjoined. If it is held that breaching doctor-patient confidentiality is in the public interest, then the processing of that medico-personal data must also be justified as an exercise of a function of a public nature (i.e. provision of healthcare) which is exercised in the public interest (for example,

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<sup>102</sup> Paragraph 8(1)(b).

<sup>103</sup> Laurie, above, n 66, p. 218.

<sup>104</sup> *Guardian Newspapers*, above, n 67, at 282.

to prevent harm). Thus there is considerable overlap when considering questions concerning the nature, scope and identity of public interest exceptions.

The existence of these exceptions does not diminish the importance of confidentiality and data protection within medical practice. Protecting the patient's privacy remains central to the provision of effective healthcare, because 'few would go to those who were unable or unwilling to keep a patient's intimate details to themselves.'<sup>105</sup> However, these exceptions enable practitioners to justify the disclosure of confidential information and avoid censure for breach of confidence or data protection, providing disclosure advances a suitable public interest.

When a defendant raises a public interest exception, the courts are required to decide whether the interest in maintaining confidentiality, or enforcing data protection, is countervailed by the other public interest. When faced with competing interests, it is for the court to achieve a just balance between the two. This balancing exercise will always begin with the public interest in protecting confidential information. The claimant's personal interest in maintaining the secrecy of their medico-personal data is eschewed. Thus in the context of disclosing genetic information, the proband's personal desire to keep such data confidential is ancillary; the central question before the courts is whether or not, in the given circumstances, the public interest is served by upholding confidentiality and data protection. The subordinate nature of the private interest was highlighted in *W v Egdell*,<sup>106</sup> wherein Sir Stephen Brown explained that although the claimant does have a private interest in maintaining doctor-patient confidentiality, the obligation 'owed to him is based on the broader ground of public interest'.<sup>107</sup> Bingham LJ also observed that while the claimant may have a personal interest in restricting the disclosure of information (which, in *Egdell*, effected the claimant's potential release from detention under the Mental Health Act 1959) 'private considerations should not be allowed to obscure the public interest in maintaining professional confidences.'<sup>108</sup> The reliance of the courts on the public interest as a justification for upholding confidentiality is a crucial element of the legal framework because, as Laurie explains, were the courts to engage in a balancing exercise involving the claimant's private interest and a countervailing public interest then 'such a balance would always weigh in favour of the latter interest.'<sup>109</sup>

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<sup>105</sup> Pattinson, above, n 9, p. 201.

<sup>106</sup> [1990] Ch 359.

<sup>107</sup> *Ibid.*, at 416.

<sup>108</sup> *Ibid.*, at 420.

<sup>109</sup> Laurie, above, n 66, p. 219.

A breach of confidentiality and data protection is only justified by reference to a countervailing interest if disclosure is *in* the public interest, as opposed to *of* public interest. Thus a degree of advancement is implied. It is therefore insufficient to merely identify a competing interest and ‘necessary to demonstrate that the breach of confidence will de facto further the competing public interest, or at least a likelihood of this.’<sup>110</sup> The benefit to the public of processing must outweigh ‘the public good of maintaining trust in the confidentiality of services’.<sup>111</sup> Additionally, no alternate way to achieve this benefit must be available to the defendant.<sup>112</sup>

The circumstances in which a public interest justification will be available are not clearly defined in the case law, although it is apparent that justification is dependent on the striking of a ‘just balance’ between the public interest in confidentiality and any competing interest.<sup>113</sup> As the Confidentiality Advisory Group (CAG) at the Health Research Authority note, the public interest ‘is not a concept usually unpacked in the abstract. Rather it is an idea given substance by the specifics of a particular case.’<sup>114</sup> Laurie characterises the public interest as a ‘relative notion which depends on a just balance between competing interests.’<sup>115</sup>

Public interest exceptions are therefore a somewhat fluid concept, retaining a degree of flexibility that permits recognition of new countervailing interests when they arise. In this way the law is able to reflect changes in societal values, technology, understanding and medical practice. Thus the door is open for the disclosure of genetic information to be recognised as being in the public interest, which leads to the question: what might that public interest be?

To identify countervailing interests in this context, Laurie suggests an appropriate starting question may be ‘which interests might be jeopardised by non-disclosure of genetic information?’<sup>116</sup> This question might return an answer of the interests in

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<sup>110</sup> *Ibid.*, p. 230.

<sup>111</sup> Department of Health, *Information Governance Review* (2013), p. 55.

<sup>112</sup> In the context of genetic information and risks, an alternative means of realising an interest may be to encourage the proband to disclose their results to family members. This, however, is argued as ineffectual.

<sup>113</sup> Laurie, above, n 66, p. 220.

<sup>114</sup> Confidentiality Advisory Group, *Principles of Advice: Exploring the concepts of ‘Public Interest’ and ‘Reasonably Practicable’*, 2012, p. 3.

<sup>115</sup> Laurie, above, n 66, p. 220.

<sup>116</sup> *Ibid.*, p. 232.

preventing harm to others, protecting public health and halting the spread of disease. Disclosure might also be in the public interest because preventing of harm to a patient's blood relatives might also protect their right to life. Disclosure might therefore be justified by reference to both the public interest and Art 2 ECHR. Alternately, it might be argued that disclosure is in the public interest because it benefits both the proband and the recipient – if a patient's blood relations are also tested, the proband's genetic information will be afforded greater clarity and utility. Or it might be argued there is a public interest in sharing genetic information generally, because large data sets with critical masses of genetic information will lead to significant improvements in genomic medicine.

An important qualifier is that it is 'necessary to demonstrate that the breach of confidence will de facto further the competing public interest, or at least a likelihood of this.'<sup>117</sup> Thus processing must 'benefit patient care or achieve some other tangible benefit that might be reasonably described as a public good'.<sup>118</sup> Additionally, an alternate way of advancing the public interest – which does not involve breaching confidentiality – must not be available. It is this latter point that poses a problem if the sharing of genetic information is proposed as being of general public interest. Although the collation of large data sets represents an opportunity for significant improvements in genomic medicine – which is arguably in the public interest<sup>119</sup> – an alternate means of collecting data, which does not require a breach of confidentiality, is available via projects such as Genomics England<sup>120</sup> (presently overseeing the 100,000 Genome Project) and the Personal Genome Project: UK (PGP: UK), which invites 'willing participants to publicly share their personal data for the greater good.'<sup>121</sup> The strong public interest in maintaining confidentiality means that any countervailing interest must be compelling, but the existence of alternate ways of obtaining genetic data weakens the argument that disclosure is generally in the public interest.

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<sup>117</sup> *Ibid.*, p. 230.

<sup>118</sup> Department of Health, above, n 111, p. 55.

<sup>119</sup> For example, the Confidentiality Advisory Group 'supports fundamentally the principle that research, and generally progressing human understanding, is in the public interest. Not least of all because most medical research is intended to contribute toward future improvements in patient care.' CAG, above, n 114, p. 5.

<sup>120</sup> <http://www.genomicsengland.co.uk>

<sup>121</sup> <http://www.personalgenomes.org/uk>

An analogy might be drawn with the case of *X v Y & Others*.<sup>122</sup> Here the court was concerned with balancing the public interest in protecting confidentiality against interests in protecting public health and freedom of the press. The case involved an unauthorised disclosure of medico-personal data to a newspaper by an employee of the claimant health authority. The data in question concerned two general practitioners with Acquired Immune Deficiency Syndrome (AIDS), who were still practicing in the UK and had sought advice from the claimant regarding their condition. The health authority obtained an interlocutory injunction restraining the newspaper ‘from publishing or disclosing to third parties or making any use whatsoever of any confidential information ... contained in [the GPs’] medical records’.<sup>123</sup> Breaching the order, the newspaper published an article entitled ‘Scandal of Docs with AIDS’, which alleged that the Department of Health and Social Security – as it then was – had refused to answer certain questions regarding healthcare practitioners with AIDS. Further coverage of the so-called ‘scandal’ was planned and, initially, it was the newspaper’s intention to reveal the identities of the GPs or, at the very least, their respective areas of expertise. The health authority made an application for a permanent injunction in the terms of the interlocutory order on grounds of breach of confidence and contempt of court. The defendants argued that any breach of confidence was justifiable by reference to the public interest in protecting public health, which necessitated a debate on whether or not clinicians with AIDS should continue to practice after they had been diagnosed with the condition. Having considered a range of expert testimony regarding the condition, its transmission and the risks associated with a breach of confidence, Rose J concluded:

‘[T]here is some public interest in knowing that which the defendants seek to publish<sup>124</sup> ... [but] those public interests are substantially outweighed when measured against the public interest in relation to loyalty and confidentiality both generally and with particular reference to AIDS patients’ hospital records.’<sup>125</sup>

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<sup>122</sup> [1988] RPC 379.

<sup>123</sup> *Ibid.*, at 401.

<sup>124</sup> *Ibid.*, at 389 Rose J acknowledged that ‘public debate about, for example, the degree of risk, notifiability and the voluntary nature of constraints on practice is, in my judgment appropriate, necessary and desirable.’

<sup>125</sup> *Ibid.*, at 395-396.

The court refused the defendants authorisation to disclose the GPs' medical records and the claimant was granted a permanent injunction. The critical point was Rose J did not consider the information the newspaper sought to reveal as advancing the public interest. Although a debate on AIDS did engage the interest in protecting public health, he explained:

'The deprivation of the public of the information sought to be published will be of minimal significance ... all the evidence before me shows that a wideranging (*sic*) public debate about AIDS generally and about its effect on doctors is taking place'.<sup>126</sup>

Rose J also observed that authorising disclosure of medico-personal data by reference to an interest in protecting public health was potentially counterintuitive. He noted that preserving confidentiality was necessary secure public health, since patients would not come forward if doctors did not respect the privacy of the information in their possession.<sup>127</sup> Neither of the GPs concerned were involved in invasive procedures and therefore the risk of transmission to their patients was appreciably low.<sup>128</sup> The risk that concerned Rose J was that – were the court to authorise disclosure of the GPs' medical records – individuals with AIDS might be discouraged from seeking medical advice because of a perception that their confidentiality would not be as robustly protected as that of other patients.

The decision in *X v Y* is arguably correct. The lack of sufficient advancement linked to the disclosure undermined the defendant's public interest arguments. The court also recognised the significance of an environment in which personal medical issues can be discussed (generally) without fear of repercussions. Patients are unlikely to be honest and receive effective treatment if they are guarded in the consulting room. For this reason, a similar objection might be raised about the disclosure of genetic information being generally in the public interest. It is unequivocal that advancing genomic medicine is in

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<sup>126</sup> *Ibid.*, at 396.

<sup>127</sup> *Ibid.*, at 386.

<sup>128</sup> In the late 1980s, when *X v Y* was litigated, there were no recorded cases of doctor to patient transmission of HIV or AIDS and only eleven known instances of patient to doctor transmission (*X v Y*, above, n 119, at 385). At the turn of the 21<sup>st</sup> Century, there were only two recorded instances to doctor to patient transmission. See Lot, F., *et al*, 'Probable transmission of HIV from an orthopedic surgeon to a patient in France' (1999) 130 *Ann Int Med* 1; also Ciesielski, C., *et al*, 'Transmission of Human Immunodeficiency Virus in a dental practice' (1992) 116 *Ann Int Med* 798.



the public interest; likewise, the debate on whether healthcare practitioners with AIDS should continue to practice was also in the public interest. However, in both circumstances, one might argue that routinely breaching doctor-patient confidence will give rise to a perception that the patient's confidentiality is not respected. In *X v Y* it was posited that AIDS patient's could be dissuaded from seeking medical advice. Similarly, a failure to respect the confidentiality of genetic information may discourage patients from obtaining genetic testing. It may of course have the opposite effect if the information, eventually, is perceived as being important to share from a societal point of view. That is, members of the public could become sensitised to the benefits of testing and sharing. The law could nudge this perception in the right direction if it allowed disclosure more readily, although prior to a change in societal values any such attempt may instead be characterised as an unwelcome intrusion into the private sphere.

The main point of debate regarding whether general disclosure of genetic information is in the public interest is advancement. Disclosure must further the public interest or be likely to do so and an alternative means of advancing the interest must not be available. In *X v Y*, since the essential facts of the disclosure – that clinicians with AIDS continued to practice in the UK – were already in the public domain, the defendant's contentions that they were acting in the public interest were rendered hollow. A similar argument might apply in respect of genetic information, since projects such as Genomics England and PGP: UK provide alternative means of advancing genomic medicine without breaching confidentiality. An argument for genetic altruism therefore fails to gain any traction.

The decision in *X v Y* offers a robust defence of confidentiality but its weakness 'lies in its failure to explain more clearly the precise nature of the concept of the public interest',<sup>129</sup> a lack of clarity that Laurie views as being 'compounded by subsequent decisions'.<sup>130</sup> The lack of clarity means that assessing whether a breach of confidentiality is in the public interest has become a relative notion dependent 'on a just balance between competing interests.'<sup>131</sup> Public interest justifications are therefore less reliant on precedent and instead display sensitivity to context. Since the balance only weighs in favour of a countervailing interest when it is likely to be meaningfully advanced, whether a sufficient degree of advancement is likely will depend on the context in which the disclosure is sought. Thus general disclosure of genetic information may not further the public interest

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<sup>129</sup> Laurie, above, n 66, p. 220.

<sup>130</sup> *Ibid.*

<sup>131</sup> *Ibid.*

because alternate avenues are available, but it does not mean that disclosure will never be in the public interest. The medical information of AIDS patients demonstrates this fact. In *X v Y* the defendant's public interest defence failed, but the opposite was true in the case of *H (a healthcare worker) v Associated Newspapers Ltd.*<sup>132</sup>

In *H* the claimant was again a practitioner infected with the HIV virus who the press sought to make certain disclosures about. Chiefly, they intended to identify the health authority for whom he worked but, in the alternative, they wished to disclose his particular specialty and the approximate date he contracted HIV. Litigated after the enactment of the Human Rights Act 1998, the fundamental tension for the courts to resolve was between the defendant's Art 10 right to freedom of expression and the claimant's Art 8 right to respect for privacy. However, the situation was complicated by the fact that the claimant was challenging the government's policy regarding healthcare practitioners diagnosed with HIV. The policy required a 'look back' exercise to be conducted and any patients who had come into contact with HIV positive clinicians to be informed of the potential risk of transmission. The claimant, after seeking advice and learning the risk of transmission within his discipline was negligible, refused access to his patients' records and sought an injunction to protect his identity, discipline and the name of the health authority by whom he was employed. Nevertheless a piece was published entitled 'Judge's gag over AIDS threat to patients', which contained clues regarding the claimant's identity. Thereafter, the defendant successfully applied for a variation of the injunction permitting further disclosure. The claimant unsurprisingly appealed and it fell to the Court of Appeal to strike a just balance between the competing interests.

Lord Phillips MR, delivering the judgment of the court 'found some measure of support for both sides of the argument',<sup>133</sup> and encapsulating the judgment of Rose J in *X v Y*, he stated:

'there is an obvious public interest in preserving the confidentiality of victims of the AIDS epidemic and, in particular, of healthcare workers who report the fact that they are HIV positive ... if healthcare workers are not to be discouraged from reporting that they are HIV positive, it is essential that all possible steps are taken to preserve the confidentiality of such reports.'<sup>134</sup>

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<sup>132</sup> [2002] EWCA Civ 195.

<sup>133</sup> Mason, Laurie, above, n 27, p. 185.

<sup>134</sup> *H*, above, n 132, at 27.

The Court of Appeal therefore recognised the importance of an environment in which personal medical issues can be discussed without fear of repercussions. However, it also accepted that the information the defendants wished to publish contained ‘features of considerable public interest.’<sup>135</sup> Lord Phillips explained:

‘It is a matter worthy of debate whether N [the health authority] should not have reacted swiftly and forcibly when faced with a healthcare worker who was challenging Department of Health Guidelines ... It is a matter worthy of debate that there is a present hiatus during which the patients of a healthcare worker with a particular speciality are not being notified that he is HIV positive ... That debate will be muted while the speciality remains unknown.’<sup>136</sup>

The context within which the defendant sought to make the disclosure – the claimant’s challenging of the ‘look back’ exercise – weighed strongly upon the Court of Appeal as there existed a strong public interest in guidelines pertaining to healthcare workers diagnosed with HIV. Yet the court simultaneously recognised that protecting the confidentiality of AIDS patients was in the public interest because, as Rose J observed in *X v Y*, it is ‘a way of protecting public health.’<sup>137</sup> It was ultimately decided that neither the claimant nor the health authority employing him could be identified per se, however, the court was not satisfied that the risk of the claimant being identified was sufficient to prohibit the defendants from publishing his speciality. He was, in the end, revealed to be a dentist. Explaining why there was an insufficient risk to justify a continued restriction on the publication of his field of practice, Lord Phillips set out the public interests that supported the defendant’s arguments,<sup>138</sup> concluding that:

‘There must be a risk that some who know the details of H’s retirement may suspect, and it can be no more than suspicion, that he is the healthcare worker in this action. Provided, however, that the other restraints ... remain in force ... we do not consider this risk justifies continuing the restraint on disclosing H’s

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<sup>135</sup> *Ibid.*, at 24.

<sup>136</sup> *Ibid.*

<sup>137</sup> *X v Y*, above, n 122, at 386.

<sup>138</sup> *H*, above, n 132, at 24.

speciality ... this restraint is inhibiting debate on what is a matter of public interest ... [and] is not justified.’<sup>139</sup>

While the court refused to authorise disclosure of the GPs’ specialties in *X v Y* because it did not advance the public interest, the opposite was considered true in *H*. The distinction between the cases rests on *H*’s challenge of the ‘look back’ exercise. In *X v Y* the fact that GPs with HIV continued to practice and the associated risks were all ready available to the public and thus nothing was advanced by disclosure. Furthermore, the GPs had sought advice to limit the possibility of transmission and disclosure may have discouraged otherwise responsible action. In *H* the Court of Appeal believed the public interest in the guidelines the claimant was challenging (and the potential health risks associated with that challenge) justified disclosure. Thus the claimant’s area of practice was considered relevant to the public debate regarding whether or not a ‘look back’ exercise should be conducted when a clinician was diagnosed with HIV. This was despite the negligible risk of transmission in dental practice. A further influence upon the court may also have been a shift in societal attitudes towards HIV in the interceding years, given the negative connotations associated with an AIDS diagnosis in the 1980s.

Public interest justifications are context sensitive and the divergent outcomes in *X v Y* and *H* provide support for the proposition that they are a ‘relative notion’, dependent on the striking of a just balance between competing interests. Neither judgment can be characterised as incorrect since the material facts at issue were sufficiently distinct. In the context of genetics, *X v Y* and *H* lend support to the proposition that disclosure of genetics risk may not be in the public interest if couched in terms of genetic altruism – since alternate routes are available by which to advance the public interest – but might be accepted as in the public interest if disclosure is raised within a different context.

As noted above, the public interest is a fluid concept. On the one hand there is a strong public interest in protecting confidentiality because patients will be encouraged to seek treatment. However, interests in protecting public health, preventing harm and stopping the spread of disease may also be engaged and justify disclosure. Thus although the GPs’ confidentiality was protected in *X v Y*, disclosure was justified in *H* because it furthered interests in public health and preventing the spread of disease and no alternate means of advancement were available. For this reason, if the general disclosure of genetic information is rejected as not advancing the public interest, because of the availability of

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<sup>139</sup> *Ibid.*, at 59.

an alternate route, this does not represent a blanket prohibition and a different justification for disclosing genetic information can be identified.

One alternate countervailing interest might be that disclosure is beneficial to both the proband and the recipient, because it improves the clarity and utility of genetic information. The question here is whether the interest engaged is a private interest. Achieving greater clarity and utility will benefit members of a family unit, but whether this is sufficient to be in the public interest is open to conjecture. It may be that since greater clarity and utility will improve therapeutic responses to genetic conditions, the interests of the proband and their blood relatives could be repackaged as part of an overriding interest in public health. The difficulty is that genetic conditions are inherited instead of contagious. Transmission occurs through reproduction and not exposure to an affected person, unlike, for example, HIV, the transmission of which requires exposure to affected bodily fluids. Therefore the public health element may not be immediately apparent. However, the courts' interpretation of the public interest has not always subscribed to strict notions of public good. An example is the decision in *R v Crozier*.<sup>140</sup> Here a psychiatrist – engaged by counsel for the defence – disclosed the contents of an evaluative report to counsel for the Crown. The report detailed how the defendant was suffering from a psychiatric illness and recommended detention pursuant to the Mental Health Act 1983. As a consequence of receiving this information, the Crown sought a variation of the judge's disposal under the Supreme Court Act, requesting substitution of the original custodial sentence for a hospital order. The variation was granted and the defendant appealed against the modified disposal, arguing that the courts should have disregarded the psychiatrist's report because it had been disclosed in breach of doctor-patient confidentiality. Absolving the psychiatrist of impropriety and dismissing the appeal, Watkins LJ observed that 'in a very difficult situation, he [the psychiatrist] acted responsibly and reasonably.'<sup>141</sup>

*Crozier* demonstrates that lines between public and private interests are difficult to draw. Varying the trial judge's disposal arguably did not engage a public interest (Crozier's crime gave no indication he posed a risk to the public) and it is 'more credible to argue that a hospital order was in the *patient's* (better) interests rather than in the *public* interest.'<sup>142</sup> Therefore it is possible to extrapolate that while genetic conditions may not be contagious – and thus do not typically affect the wider public – it may nonetheless be held

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<sup>140</sup> (1990) 8 BMLR 128.

<sup>141</sup> *Ibid.*, at 213.

<sup>142</sup> Laurie, above, n 66, p. 222.

to be in the public interest that genetic information is disclosed. The problem with constructing the interest as providing greater clarity and utility to the proband's genetic information is that the interest is couched in terms of individual – as opposed to public – benefit. Public good would depend on a trickle down effect – i.e. that improving the clarity and utility of one individual's genetic information improves therapeutic responses for all patients who suffer the identified condition. Constructing the public interest in such a way also shifts the reason disclosure is sought away from the risks faced by blood relatives and instead focuses on the potential benefits to the proband. If a duty to disclose is to be a justifiable and sustainable departure from confidentiality and data protection, then it must be in the public interest to disclose genetic information to the proband's blood relatives and not because it is in the interests of the proband. A further problem may if the benefit is couched in terms of broadly improving genetic medicine because the argument concerning alternative routes is reengaged, questioning whether disclosure sufficiently advances the public interest.

As Laurie suggests, an appropriate question to consider is 'which interests might be jeopardised by non-disclosure of genetic information?'<sup>143</sup> This question might immediately return an answer of the interest in preventing harm to others<sup>144</sup> and halting the spread of disease. These interests are important when treating patients with communicable diseases and 'have clear potential application in the context of genetics'.<sup>145</sup> In the context of HIV, it is justifiable to disclose a patient's HIV status to a sexual partner, who is then able to make informed choices regarding unprotected intercourse. Subsequent to disclosure, if 'the partner chooses to act responsibly infection will not take place and the public interests that served as justification for breaching the patient's confidentiality will be furthered.'<sup>146</sup> Therefore, as Laurie writes,

'it might be argued that the prevention of harm to others and the reduction of the incidence of genetic disease are legitimate public interests that can be furthered through disclosure of genetic information.'<sup>147</sup>

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<sup>143</sup> *Ibid.*, p. 232.

<sup>144</sup> Harm in the context of the nondisclosure of genetic information is discussed further in chapter four.

<sup>145</sup> Laurie, above, n 66, p. 231.

<sup>146</sup> *Ibid.*, p. 231.

<sup>147</sup> Laurie, above, n 66, p. 232.

However, justifying disclosure by reference to a public interest in the prevention of disease is problematic. This is because there is no certainty that the public interest will be furthered in any meaningful way, which undermines the justification for derogating from confidentiality and data protection. Genetic diseases are inherited, thus for the public interest to be furthered a disclosure of genetic information must be likely to effect reproductive choices. But, as Laurie notes, ‘there is no certainty that even if disclosure is made people will no longer reproduce or will only reproduce in a “responsible” fashion.’<sup>148</sup>

Alternately, where a potential for harm exists, the courts are willing to justify a breach of confidentiality as in the public interest. A case in point – although not strictly within the context of medicine – is *W v Egdell*.<sup>149</sup> Here the Court of Appeal held that a disclosure regarding a prisoner’s mental state, made by his psychiatrist, was in the public interest. The claimant was a prisoner who had been convicted of five counts of manslaughter by reason of diminished responsibility and had been detained without limit in a secure hospital. Twelve years after his conviction he applied to a mental health review panel for transfer to a less secure facility, with a long-term view of returning to the community. The defendant was engaged as an independent consultant but his review of the claimant’s mental state was unfavourable. The application was withdrawn but the psychiatrist – aware the claimant was due for a routine review under s71(2) Mental Health Act 1983 and concerned that his report would not be included in the prisoner’s notes – disclosed his findings to the relevant authorities. The Court of Appeal held that disclosure was justified by reference to the public interest in preventing harm, Bingham LJ explaining that where there existed ‘a real risk of consequent danger to the public’<sup>150</sup> it was in the public interest for the psychiatrist ‘to take such steps as are reasonable in all the circumstances to communicate the grounds of his concerns to the responsible authorities.’<sup>151</sup>

Although concerned with the risk posed by a dangerous criminal, *Egdell* provides a sense of the compelling nature of the public interest in preventing harm. Thus if the disclosure of genetic information can be shown as preventing harm to the proband’s blood relatives, it may countervail the interest in protecting doctor-patient confidentiality.

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<sup>148</sup> Laurie, above, n 66, p. 234.

<sup>149</sup> [1990] 1 All ER 835.

<sup>150</sup> *Ibid.*, at 424.

<sup>151</sup> *Ibid.*

Applying the interest in preventing harm to genetics engages two important questions. Firstly, what harm is prevented by disclosure,<sup>152</sup> and, secondly, can harm ‘be prevented by disclosure in the context of genetics’?<sup>153</sup> The focus here is the latter question; the former is one to which this work will return in subsequent chapters.

In circumstances where a cure is available for the condition the patient is suffering, disclosure to his or her blood relatives can prevent harm because it expedites access to the cure. When therapeutic responses short of a cure are available, disclosure may also prevent harm because it facilitates access to medical interventions which may alleviate or minimise symptoms of the disease. However, if treatment is ineffective, especially invasive, painful or difficult to obtain, then whether disclosure prevents harm is somewhat debatable.<sup>154</sup>

An example of the potential of disclosure to prevent harm is provided by haemochromatosis.<sup>155</sup> There is currently no cure available; however, the condition can be alleviated through periodic phlebotomy – bloodletting – which, if sought preemptively, can reduce the risk of fibrosis. Furthermore, haemochromatosis is a common recessive disorder, meaning that the chances of relatives sharing the condition are 25 to 50 per cent. Collectively, ‘all of this might be taken as the basis of a strong case to justify disclosure to potentially affected individuals.’<sup>156</sup> Similar arguments could be advanced in the case of breast cancer – or, perhaps, cancers generally – where early intervention may reduce the risk of the disease manifesting either through chemoprevention or surgery.<sup>157</sup> In these circumstances disclosure is likely to further the public interest because it facilitates access to medical interventions and thus prevents – or minimises – harm to the proband’s blood relatives.<sup>158</sup> The public interest would only be furthered, however, when treatment is

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<sup>152</sup> The concept of harm in cases involving genetic information is explored in chapter four.

<sup>153</sup> Laurie, above, n 66, p. 234.

<sup>154</sup> Takala, T., Gylling, H., ‘Who should know about our genetic make up and why?’ (2000) 26 *Journal of Medical Ethics* 171.

<sup>155</sup> The condition causes excess iron to accumulate within the body and fibrosis occurs where the iron collects. Common related conditions include liver cirrhosis, diabetes and heart failure. It is one of the most common recessive conditions in the UK, with around one in 500 possessing the deleterious genetic trait.

<sup>156</sup> Laurie, above, n 66, p 232.

<sup>157</sup> For an example of these circumstances, see BBC News, ‘Should I have breast cancer gene test?’ 14 July 2011; see also, ‘Rackheath woman’s tough decision to have her breasts removed after her mum died from cancer’, Norwich Evening News, 23<sup>rd</sup> October 2012.

<sup>158</sup> It goes without saying that tangible benefits need not be limited to just a cure or treatment. Wider societal or public benefits also exist, with one such example being the advancing knowledge



available for the relevant condition, since ‘if disclosure is made to avoid an ancillary harm such as psychological distress or psychiatric disturbance ... there is less of a guarantee that the harm in question will de facto be avoided.’<sup>159</sup> In such circumstances, disclosure may actually conflict with the public interest in preventing harm. The case of *Re YZ*<sup>160</sup> implies that disclosing genetic information in absence of a tangible benefit (i.e. a cure or treatment) may not be in the public interest. Herein Baker J refused to order genetic testing for two young boys involved in care proceedings when the biological father asserted he may have Huntington’s Disease, on the basis that the disadvantages of testing – including emotional and psychological harm – outweighed the advantages from the perspective of the boys.

Justifying the disclosure of genetic information by reference to a public interest in preventing harm might also engage Art 2 ECHR, which, in turn, strengthens the claim that disclosure is in the public interest. Logically, the prevention of harm – particularly in circumstances involving potentially fatal conditions, such as cancers – might also protect the right to life of patients’ blood relations. If engaged, the status of Art 2 as absolute means the public interest in confidentiality and the proband’s Art 8 right to respect for privacy would be countervailed by the right to life of family members. Disclosure of the proband’s genetic information would thus be a justified derogation from confidentiality and data protection.

Art 2(1) ECHR reads ‘everyone’s right to life shall be protected by law’. In broad terms, this means that the state ‘must not cause the death of any person’.<sup>161</sup> However, Art 2 also imposes a positive obligation on the state ‘to take appropriate steps to safeguard the lives<sup>162</sup> of those within its jurisdiction’,<sup>163</sup> with the caveat that steps must not amount to a ‘an impossible or disproportionate burden on the authorities.’<sup>164</sup> In *Association X v United*

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of certain diseases. The important point, however, is that wider, societal benefits do not necessarily prevent harm to the individual to which the information is to be disclose. This is because advancing knowledge of disease is a long term goal and thus may take years to produce tangible results.

<sup>159</sup> Laurie, above, n 66, p. 233.

<sup>160</sup> [2013] EWHC Fam 935.

<sup>161</sup> Haggett, E., *The Human Rights Act 1998 and Access to NHS Treatments and Services: A Practical Guide* (The Constitutional Unit, UCL, London: 2001), p. 14.

<sup>162</sup> A ‘life’ in this context is one that has been born – the right to life does not apply *in utero* or *in vitro*. See *Evans v Amicus Healthcare Ltd* [2004] EWCA Civ. 727.

<sup>163</sup> *LCB v United Kingdom* [1998] 27 EHRR 212, at 36.

<sup>164</sup> *Osman v United Kingdom* [2000] 29 EHRR 245.

*Kingdom*<sup>165</sup> the Commission considered the duty to the state under Art 2 included the provision of adequate and appropriate health care. This interpretation of the right to life is also evident in *LCB v United Kingdom*.<sup>166</sup> Here the claimant was a woman diagnosed with leukaemia allegedly caused by her father's – a former RAF servicemen – exposure to radiation during nuclear tests conducted on Christmas Island in the late 1950s. The claimant alleged that 'the failure of the British Government to warn her parents of the potential health risk to her by virtue of her father's presence at the nuclear testing' was a breach of Art 2.<sup>167</sup> The question for the European Court of Human Rights (ECtHR) was whether 'the State did all that could have been required of it to prevent the applicant's life from being avoidably put at risk.'<sup>168</sup>

The ECtHR dismissed the claim because a causal link between the father's exposure to radiation and the daughter's cancer had not been established. However, the judgment did appear to affirm that 'the state could have been required to take steps to warn and advise if it had appeared likely at the time that the irradiation of the father would endanger the health of a daughter not yet conceived.'<sup>169</sup> *LCB* therefore indicates that when a state – through the medium of a public authority – is aware that a particular individual<sup>170</sup> is likely at risk of harm, it is obliged to take appropriate steps to safeguard their right to life, providing these steps are not impossible or disproportionately burdensome. The obligation arises when it is 'likely' that an individual's Art 2 rights are endangered. Thus the claimant need only be vulnerable<sup>171</sup> and it is not necessary for harm to be certain, which is important in respect of genetics because there is no guarantee that diseases *will* be shared by descendants of a common gene pool, only a statistical likelihood.

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<sup>165</sup> *Application No 7154/75* 14 DR 31.

<sup>166</sup> [1998] 27 EHRR 212.

<sup>167</sup> Harvey, R., Mugnai, E., *The 'Right to Life': Commentary on Article 2* (Children's Legal Centre, 2002), p. 13.

<sup>168</sup> *LCB*, above, n 166, at 36.

<sup>169</sup> Lord Lester, Lord Pannick, Herberg, J., *Human Rights Law and Practice*, 3<sup>rd</sup> ed. (Butterworths, London: 2009), at 4.2.55.

<sup>170</sup> Or, following *LCB*, a future individual, which raises interesting questions within the context of genetic testing and reproductive decision-making and how these reconcile with the interpretation of the right to life as existing only post-natal. These are beyond the scope of this thesis.

<sup>171</sup> In *Rabone v Pennine Care NHS Trust* [2012] UKSC 2, Lord Dyson (at 23) 'observed that the Strasbourg Court had repeatedly emphasised the vulnerability of the victim as a relevant consideration.' Cobb, D., 'The Supreme Court and the state's duty to protect vulnerable groups: the effect of *Rabone*' (2012) SLT 75, p. 77.

If the rationale from *LCB* is applied to genetic information, the argument forms that once a deleterious trait is identified in the proband's genome, the NHS becomes aware of the potential risks to the health of the patient's blood relations. The right to life is not a right to exist – a fact demonstrated by litigation concerning the withdrawal of life-sustaining treatment.<sup>172</sup> Instead Art 2 operates in the medical context to safeguard the right to life through the provision of an appropriate standard of healthcare.<sup>173</sup> Therefore, to protect the Art 2 rights of the proband's family the NHS may be obliged to disclose the patient's genetic information. While there would remain a strong public interest in protecting the proband's confidentiality in these circumstances, the right to life – as an absolute right – would countervail this interest and justify disclosing genetic information to the proband's blood relatives. The caveat is that safeguarding the right to life must not be impossible or disproportionately burdensome. Disclosure would thus only be appropriate when a therapeutic response is available for the relevant genetic condition and the recipient of the information is identifiable.

One difficulty with justifying disclosure by engaging Art 2 ECHR is that making a disclosure could be characterised as disproportionately burdensome upon the NHS. Consequentially, one might argue that it is not an appropriate step to safeguard the right to life. A comparable objection has been raised in the United States in litigation concerning a duty to warn blood relations about transmissible genetic risks. In *Pate v Threlkel*<sup>174</sup> it was accepted that 'to seek out and warn various members of a patient's family would often be difficult or impractical and place a heavy burden upon the physician.'<sup>175</sup> The underlying concern was that an obligation to disclose would divert resources away from clinical practice. However, the argument was rejected in *Safer v Estate of Pack*,<sup>176</sup> wherein the court concluded 'a duty to warn of avertable risk from genetic causes ... is sufficiently narrow to serve the interests of justice.'<sup>177</sup> It was concluded that because genetic diseases are hereditary '[t]he individual or group at risk is easily identified, and substantial future harm is easily ... minimized by a timely and effective warning.'<sup>178</sup> In the context of Art 2

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<sup>172</sup> E.g. *Airedale NHS Trust v Bland* [1993] AC 789.

<sup>173</sup> Although what is meant by 'an appropriate standard' is unclear, see *X v Ireland* (1974) 7 DR 78.

<sup>174</sup> 661 So 2d 278 (Supreme Court of Florida 1995).

<sup>175</sup> *Ibid.*, at 282.

<sup>176</sup> 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996).

<sup>177</sup> *Ibid.*

<sup>178</sup> *Ibid.*

ECHR, the state is obliged to take *appropriate* steps to safeguard the right to life which are not *disproportionately* burdensome. It is axiomatic that taking steps to protect individuals' Art 2 rights will incur a degree of burden; that burden, however, must not be disproportionate. Thus a distinction can be drawn between disclosing to identifiable and unidentifiable blood relations, with it only being appropriate to disclose genetic information to those relations who are easily identified.<sup>179</sup> Because public authorities are not obliged to act when the steps available are disproportionately burdensome, this would allow scope for ruling that, when relatives are not identifiable, the disclosure of genetic information does not constitute an appropriate means of safeguarding Art 2 rights.

The public interest in preventing harm and Art 2 ECHR would appear to provide a strong basis for justifying the disclosure of genetic information to blood relations, countervailing the interest in maintaining confidentiality and data protection. However, Laurie argues that healthcare practitioners in possession of genetic information are 'restricted',<sup>180</sup> which draws into question the capacity of disclosing genetic information to prevent harm. Laurie explains that while it is possible to establish the abstract probability of an individual possessing a deleterious genetic trait, in practice it is impossible without screening to pinpoint which individuals actually possess the gene in question. He suggests that effective disclosure would therefore require the information to be made available 'to a wide circle of persons with possible diminishing utility.'<sup>181</sup> The proband's confidentiality would therefore 'be breached on many occasions with unpredictable, and possibly minimal, results.'<sup>182</sup> The question therefore whether disclosure can be in the public interest if it is disproportionately burdensome upon the interests of the proband or is of diminishing utility. Laurie distinguishes between monogenic diseases, multifactorial conditions and familial predispositions, positing that it is less clear cut disclosure will further an interest in preventing harm or safeguarding the right life when the proband's genome contains a deleterious trait of the latter varieties. The counterpoint to this objection is that when a familial predisposition to particular disease is identified harm can be prevented, or the right to life safeguarded – in turn furthering the public interest – if access to screening and preemptive treatment is facilitated through disclosure.

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<sup>179</sup> The identifiable claimant is an important aspect of the proposed duty and is discussed further in chapter five.

<sup>180</sup> Laurie, above, n 66, p. 234.

<sup>181</sup> *Ibid.*

<sup>182</sup> *Ibid.*

A further dimension to an argument that the Art 2 rights of blood relations countervail the public interest in confidentiality is s6 Human Rights Act 1998. Section 6(1) states ‘it is unlawful for a public authority to act in a way which is incompatible with a Convention right.’ Therefore, if familial genetics engage Art 2 ECHR and disclosure is considered an appropriate step to safeguard the right to life of blood relations, then the NHS would be obliged to disclose the proband’s genetic information to those relatives who may ‘share’ the deleterious trait. In this case, the argument for a duty to disclose also becomes more compelling. This is because disclosure would be necessary for the NHS to act compatibly with Art 2 ECHR and a duty would protect the convention rights of the proband’s blood relatives.

#### *Part IV: Outlining the Case for a Duty to Disclose*

This chapter has explored the public interest that justifies disclosing genetic information to the proband’s blood relations. It has been argued here that disclosing genetic information – specifically in circumstances when a cure or treatment is available – furthers the public interest in preventing harm and is consistent with Art 2 ECHR. It has been argued that these interests countervail the public interest in maintaining confidentiality and data protection and justify breaching doctor-patient confidentiality. The question therefore arises, if disclosure of genetic information can be justified by reference to a public interest, why is it necessary to create a duty to disclose? Subsequent chapters will explain how a duty may be constructed; here the case for why a duty is necessary will be outlined.

Critics may argue that disclosures could be facilitated without introducing a new duty, particularly if disclosure is in the public interest. Certainly, there will be minimal need for judicial creativity if an exception to breach of confidence is accepted as the way forward, since the courts have already shown in *Crozier* that public and private interests will be reconciled where it is in the interests of justice. Furthermore, as doctor-patient confidentiality is a cornerstone of medical practice, an argument may be made that authorising disclosures through exceptions to confidentiality and data protection would allow healthcare practitioners to engage with and appreciate their legal obligations. There is some merit to this point because clinicians are exposed to a variety of professional literature regarding the balancing of competing interests demanded by a decision to disclose. Approaching the familial aspects of genetic information through an exception to confidentiality and data protection may therefore suit the medical profession.

The problem with this approach is that the circumstances when public interest exceptions apply are not clearly defined. Although this grants public interests a measure of fluidity, it means that exceptions to breach of confidence are uncertain. It has argued here

that disclosing genetic information is consistent with the public interest in preventing harm and Art 2 ECHR, but because balancing competing interests involves an element of discretion, it does not follow that because an exception exists it will be consistently applied. One reason for this might be that, although disclosure is in the public interest, genetic information might be communicated through the proband and a breach of confidence avoided. It would depend upon the context of the situation, but it is possible that the existence of an alternative means of disclosing genetic information could lead to the courts refusing to authorise disclosure. The effectiveness of disclosure via the proband is debatable, however, because ‘geographical, social and emotional factors can mean that communication does not happen.’<sup>183</sup> Furthermore, studies have shown that the uptake of genetic screening (and, consequently, access to preemptive treatments) is virtually doubled when clinicians make the disclosure,<sup>184</sup> which suggests that communication by healthcare practitioner is a more effective means of communicating information about genetic diseases than relying on the patient him- or herself.

A duty to disclose would obligate clinicians to make disclosure in particularly circumstances and, in this way, introduce a measure of certainty regarding when confidentiality and data protection can be breached. Though it has been posited that disclosing genetic information is in the public interest, when public interests necessitate disclosure is based on the balancing of competing interests. The decision therefore incorporates a degree of discretion, thus subjective interpretation of clinical guidance will influence the outcome of the balancing exercise. More significantly, there is no means of censure for failing to disclose information, a point to which this work returns below. A duty to disclose would create a framework within which disclosure is necessary when certain conditions are met. Thus an aspect of clarity consistency could be achieved, since for a clinician to discharge their duty they would need to comply with the appropriate standard of care. In order for doctors to effectively discharge their duty, the standard of care would need to be sufficiently defined for them to engage with, setting a minimum threshold of behaviour in respect of disclosure. An ill-defined standard of care would mean the duty would be inaccessible and the medical profession would be unable to understand their legal obligation. Since the standard of care would indicate what behaviour is expected to discharge a duty to disclose, healthcare providers would know the scope of their obligation to the blood relations of a proband with a deleterious genetic

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<sup>183</sup> Lucassen, A., and Parker, M., ‘Confidentiality and Sharing Genetic Information with Relatives’ *The Lancet* vol. 375, 1 May 2010, p. 1507.

<sup>184</sup> Suthers, G.K., *et al*, ‘Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder’ (2006) 43 *J Med Genet* 665.

trait.<sup>185</sup> In plain terms, the existence of a duty to disclose means the balancing exercise necessary to evaluate whether a breach of confidence is justifiable has all ready been undertaken.

A duty to disclose may be characterised as attempting to remove the element of discretion from decisions about breaching doctor-patient confidentiality, but instead its aim is to provide a framework within which clinical discretion does not disadvantage those who would be harmed by nondisclosure. It is trite that discretion is a necessary component of medical practice, however, unchecked it can lead to inconsistency and this is particularly evident when considering the balancing exercise applied to breaches of confidence. Although guidance attempts to introduce a measure of objectivity by encouraging clinicians to consider disclosure from the perspective of the patient and the recipient, the balancing will to some extent depend upon the healthcare practitioner's experiences and beliefs. Therefore it is entirely possible for individual clinicians to come to different conclusions regarding the same deleterious trait. Thus clinician one might disclose said trait because to do so further a public interest in preventing harm, while clinician two may consider the balance as weighing in favour of protecting confidentiality. Both of these outcomes are justifiable by reference to a public interest, yet only the decision to disclose is likely to be a candidate for judicial scrutiny because the potential recipient when disclosure does not occur has no standing in confidentiality. The inconsistency is also problematic as it creates something of a postcode lottery. A duty to disclose could introduce a measure of consistency because the standard of care necessary to discharge the duty would require doctors to disclose when particular circumstances arose. The balancing exercise between competing interests would therefore all ready be complete. A duty to disclose, however, would not remove discretion entirely and therapeutic privilege would continue to exist, but arguably therapeutic privilege would only arise in circumstances involving disclosure where no cure or treatment is available. Thus therapeutic privilege would compliment rather than conflict with a duty to disclose.

A duty would, arguably, through the standard of care, introduce a measure of consistency to decisions on disclosure and recognise the interests of blood relations in being informed of their genetic conditions. The scope of the duty proposed herein is relatively narrow and it would only arise when a treatable genetic disease is identified. The duty would thus be discharged once details of the proband's deleterious trait are communicated to identifiable relations. An analogy can be drawn between a duty to disclose genetic risks and a duty upheld in the United States and Australia to sexual

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<sup>185</sup> The standard of care is discussed in detail in chapter six.

partners of patients with HIV:<sup>186</sup> the duty arises at a specific point (diagnosis) and is discharged at an equally specific point (communication of the diagnosis to the patient). If a healthcare practitioner negligently fails to inform the patient of their HIV positive status and a sexual partner becomes infected, liability accrues because the most effective precaution – warning the patient – has not been taken. It must be noted that in the context of HIV, it is the patient's condition that poses a risk to sexual partners, thus apprising them of their diagnosis enables them and their partner to exercise precautions.<sup>187</sup> The patient's genetic condition does not pose a risk to others, thus informing the patient is of limited value to blood relatives because it does not necessarily enable the taking of precautions because genetic information is not always communicated. Furthermore, as noted previously, uptake of genetic screening (and thereby access to preventative therapies or earlier treatment) is increased when healthcare practitioners make the disclosure, indicating the clinical benefits of this approach.<sup>188</sup>

However, the critical reason confidentiality and data protection are an unsuitable means for facilitating disclosure of genetic information is because neither framework is capable of recognising harm to individuals other than the confider/data subject. Confidentiality and data protection focus on the individual to whom the information being processed pertains, protecting the secrecy of their medico-personal data and the integrity of doctor-patient relationship. Legal redress is available to those who suffer an unauthorised disclosure of confidential data or whose data is processed unlawfully, although the law does provide a number of exceptions which doctors can rely on to justify making a disclosure. However, confidentiality and data protection do not recognise the interests of third parties who are harmed because particular information was not disclosed.

Thus a duty to disclose could recognise the potential harms the proband's blood relations can experience should genetic risks be withheld. The critical aspect here is what constitutes harm in the genetic context and this is a point to which this work returns in chapter four. The issue for present purposes is that if nondisclosure is recognised as harmful but information is withheld, the current legal paradigm provides no redress for those who have suffered harm because information was not released. In this way, a duty to

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<sup>186</sup> See *Reisner v The Regents of the University of California*, (1995) 37 Cal Rptr 2 d 5180; *BT v Oei* [1999] NSWSC 1082; *PD v Harvey* [2003] NSWSC 487.

<sup>187</sup> In the event the doctor's duty is disclosed but the patient acts recklessly, then in the UK the patient becomes subject to criminal sanctions.

<sup>188</sup> Suthers, G.K., Armstrong, J., McCormack, J., and Trott, D., 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder' (2006) *J Med Genet* 43, 665–670.



disclose would recognise the familial aspect of genetics, the potential for harm and the necessity of protecting the interests of blood relations. The focus of confidentiality and data protection upon the data subject, the proband in this context, means that recognising and redressing harm beyond that caused by unauthorised disclosure or processing is unachievable, even though disclosure of genetic risks is arguably in the public interest. The confidentiality/data protection paradigm thus eschews the vulnerable position of the proband's blood relations. The shared nature of genetic information means it is not typical personal data, therefore adhering to the current legal paradigm would not recognise the broader issues that arise when deleterious traits are isolated within the proband's genome. Although it is acknowledged that doctor-patient confidentiality and data protection must be respected insofar as is possible – to maintain the level of trust necessary to effectively treat patients – data secrecy must yield insofar as is necessary to prevent harm to others.

Genes are 'shared' and the familial dimension to genetic testing means that the law has to look beyond the current paradigm of confidentiality and data protection. It must adapt and recognise the broader familial implications of genetic information and it is argued here that it should do so in circumstances where disclosure of the proband's deleterious genetic traits can prevent harm to blood relations. In the subsequent chapters, this work will outline the basis of a duty to disclose, the concept of harm and how such a duty might be realised through the tort of negligence.

### **3. FOUNDATIONS OF DUTY AND DISCLOSURE AT COMMON LAW**

#### *Introduction*

The common law obligation of confidentiality requires healthcare practitioners to respect the confidences of their patients and data protection governs when information may be lawfully processed. The legal framework provides patients with redress when disclosure or processing occurs without authorisation or sufficient justification. The problem in the context of genetics is confidentiality and data protection are not suitable vehicles for claims by blood relations flowing from nondisclosure of the proband's genetic information. English tort law does not recognise a duty to rescue, thus no general obligation exists to act in the best interests of third parties 'however reasonably or probably ... loss or damage might have been anticipated.'<sup>1</sup> Thus the proband's family must demonstrate a duty of care is owed to them by the proband's clinician, the duty has been breached, and that breach is causative of the harm sustained.

There is a paucity of case law addressing the complexities of genetic information and risks but claims concerning medical disclosure have been articulated in negligence both in the UK and United States. Claimants have been owed duties of care in respect of the disclosure of information, risks and alternative treatments.<sup>2</sup> The duty of care articulated here builds upon the duties articulated within the doctor-patient relationship and argues in favour of an extension of a healthcare practitioners' duty to particular third parties. The US judiciary has grappled with a duty to disclose medical risks beyond the therapeutic relationship, but the UK courts have only dealt with nondisclosure of medical risks within the context of the doctor-patient relationship. Thus no precise analogy exists in UK tort law, although cases have arisen concerning disclosure of risks to third parties. American tort law, in contrast, has an established line of case law regarding a duty to disclose both physical and medical risks, including genetically transmissible diseases. Though no perfect analogy exists domestically, some comparisons may be drawn with the duty to secondary victims. Secondary victims are claimants who are proximate to the defendant by virtue of an intermediate party and – although important distinctions do exist

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<sup>1</sup> *Home Office v Dorset Yacht Co Ltd* [1970] AC 1004 *per* Lord Diplock at 1060. His Lordship went on to explain '[t]he very parable of the good Samaritan (Luke 10 v. 30) ... [illustrates] an omission which was likely to have as its reasonable and probable consequences damage to the health of the victim ... but for which the priest and Levite would have incurred no civil liability in English law.'

<sup>2</sup> For example, see *Sidaway v Bethlem Royal Hospital & Maudsley Hospital* [1985] AC 871; *Pearce v United Bristol Healthcare NHS Trust* [1999] 1 PIQR 53; *Chester v Afshar* [2005] 1 AC 134; *Birch v University College London Hospital* [2008] EWHC 2237; *Nadine Montgomery v Lanarkshire Health Board* [2010] CSOH 104. From the US, see *Tarasoff v The Regents of the University of California* 529 P 2d 55 (Cal. 1974).

– proximity plays a comparably crucial role in determining liability. At a higher level of abstraction, it might also be argued that liability to secondary victims is indicative of the courts accepting claims by third parties, though subject to rigorous thresholds.

Before examining the paucity of domestic case law focusing on the disclosure of risks to third parties, it is necessary to briefly consider the clinician's duty of disclosure to patients. This is an important reference point in a discussion of a duty to disclose to blood relations because the scope of any such obligation cannot be broader than that of the duty to patients. There is a risk of undermining the doctor-patient relationship if the duty to blood relations is more robust than the duty to patients. It is thus important to establish the scope of healthcare practitioners' obligation to disclose in respect of patients before considering the mechanics of a duty to the proband's family.

The underlying focus of the duty to disclose also warrants consideration at this early stage. Traditionally the tort of negligence is a route for remedying harms carelessly inflicted upon the claimant and 'setting standards for employers ... drivers, manufacturers, healthcare professionals and many others whose carelessness may cause harm.'<sup>3</sup> Negligence is therefore 'happiest when faced with damage that arises in knotty problems involving collisions between strangers, preferably with lots of broken limbs.'<sup>4</sup> Stapleton describes harm as the gist of a negligence action,<sup>5</sup> thus an important question that arises in respect of a duty to disclose is what is the harm? The question is directly addressed in the following chapter. A necessary precursor to an analysis of the concept of harm is discussion of the fundamental premise of a duty to disclose: specifically, whether the duty is concerned with protecting familial interests in genetic risk or recognising and remedying harm arising from nondisclosure.

Questions of interest and wrongdoing are typically collated because 'negligence is not actionable unless it involves the invasion of a legally protected interest'.<sup>6</sup> By way of example, a claim arising from a road traffic accident simultaneously protects the claimant's interest in physical integrity *and* recognises and remedies the harm caused by the negligence. Concepts of interest and wrongdoing are symbiotic in this circumstance; when the negligence is nondisclosure, a duty may protect an interest in knowing information or

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<sup>3</sup> *Hatton v Sutherland* [2002] EWCA Civ. 76 *per* Hale LJ at 14.

<sup>4</sup> Chico, V., *Genomic Negligence: an interest in autonomy as the basis from novel negligence claims generated by genetic technologies* (Routledge-Cavendish: London, 2011), p. 16.

<sup>5</sup> Stapleton, J., 'The Gist of Negligence. Part I: Minimum Actionable Damage' (1988) 104 LQR 213.

<sup>6</sup> *Palsgraf v Long Island Railway Co* 59 ALR 1253 (New York Court of Appeals, 1928) *per* Cardozo J at 99.

recognise and remedy harm caused by the failure to disclose. The distinction is crucial because the focus of the duty will fundamentally differ dependent on the perspective adopted. A duty concerned with protecting an interest is breached – and harm inflicted – when the relevant interest is frustrated, examples including the torts of battery and false imprisonment, which protect interests in bodily security and liberty respectively.<sup>7</sup> A duty that recognises and remedies a harm requires a greater interference with the claimant than the frustration of their interest. Thus negligence typically requires physical or non-physical injury in addition to an interference with a legally recognised interest. As a secondary victim, for example, it is insufficient to demonstrate an interference with an interest in psychical integrity, which could take the form of grief, stress or anxiety. For a negligence claim to exist, a claimant must suffer harm; for secondary victims, this harm takes the form of a recognised psychiatric disorder.<sup>8</sup>

Thus it is necessary to explore the underlying purpose of a duty to disclose. The central consideration is whether such a duty can be reconciled with the traditional focus of negligence on remedying harm or – alternately – whether it should be construed as protecting the interests of the proband's blood relations. The paradigm within which a duty to disclose fits will then form the basis of the discussion of the relevant harm in chapter four. In advance of discussing the underlying rationale of duty to disclose, it is necessary to establish the contextual framework. Thus this chapter will briefly revisit the historical development of duty of care. Thereafter it will consider whether lessons can be learned from the development of the duty to secondary victims, which concerns a model of liability with which careful analogies might be drawn. The chapter will then return to the question what is the underlying premise of a duty to disclose, before outlining the scope of the clinician's duty of disclosure to patients. The chapter will then conclude by examining key cases from the UK and the US engaging with the issue of disclosure to third parties.

### *The Evolution of Duty*

The duty of care is a cornerstone of modern negligence; in plain terms, the existence of a duty of care transforms a defendant's conduct from negligence in fact to negligence in law.

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<sup>7</sup> On Battery, see *Wilson v Pringle* [1987] QB 287; *Collins v Wilcock* [1984] 3 All ER 374; *Re B (Consent to Treatment: Capacity)* [2002] EWHC 429 (Fam.) where the claimant successfully argued that continuing treatment once she had withdrawn her consent constituted battery. On false imprisonment, *Meering v Grahame-White Aviation Co Ltd* (1919) 122 LT 44, wherein the claimant successfully sued for false imprisonment despite being unaware that he was imprisoned at the time; *White v W P Brown* [1983] CLY 972, when 15 minutes of detention by a store detective amounted to false imprisonment.

<sup>8</sup> *Alcock v Chief Constable of South Yorkshire* [1992] 1 AC 310.

Modern understanding of duty begins with the seminal judgment of Lord Atkin in *Donoghue v Stevenson*, wherein he created the neighbour principle.<sup>9</sup> Articulating the scope of duty, his Lordship famously stated ‘in law you must not injure your neighbour’ and defined ‘neighbours’ as

‘persons so closely and directly affected by my act that I ought to have them in contemplation as being so affected when I am directing my mind to the acts and omissions called into question.’<sup>10</sup>

The neighbour principle determined a duty existed when it was reasonably foreseeable that injury would occur to person or persons with whom the defendant was sufficiently proximate. The judgment of Lord Atkin developed an earlier attempt to establish a test for duty by Brett MR in *Heaven v Pender*,<sup>11</sup> an exercise he subsequently attempted to resuscitate (as Lord Escher) in *Le Lievre v Gould*.<sup>12</sup>

*Donoghue* established the modern tort of negligence and provided a single, unifying test for duty of care. However, the neighbour principle was a broad concept and ‘little was said about how the principle might be confined; it was not limited by reference to any particular type of loss.’<sup>13</sup> Subsequently the courts attempted to refine the neighbour principle and, initially, attempts were made to limit it by reference to the narrow *ratio* of *Donoghue*.<sup>14</sup> However, during the 1960s and 1970s, the judiciary favoured trailblazing over consolidation, first recognising a duty of care in respect of negligence

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<sup>9</sup> [1932] AC 562. The claimant suffered shock and gastroenteritis after having imbibed some ginger beer that allegedly contained the decomposing remains of a snail. The case is commonly noted as marking the birth of modern negligence.

<sup>10</sup> *Ibid.*, at 580.

<sup>11</sup> (1882-83) LR 11 QBD 503 at 509: ‘whenever one person is by circumstances placed in such a position with regard to another that every one of ordinary sense who did think would at once recognise that if he did not use ordinary care and skill in his own conduct with regard to those circumstances he would cause danger of injury to the person or property of the other, a duty arises to use ordinary care and skill to avoid such danger.’

<sup>12</sup> [1893] 1 QB 491 at 497: ‘If one man is near to another, or is near to the property of another, a duty lies upon him not to do that which may cause a personal injury to that other, or may injure his property. For instance, if a man is driving along a road, it is his duty not to do that which may injure another person whom he meets on the road, or to his horse or his carriage.’

<sup>13</sup> Chico, above, n 4, p. 20.

<sup>14</sup> This would have limited the case to issues of product liability and manufacturing. For example, see *Farr v Butters Bros & Co* [1932] 2 KB 606 *per* Scrutton LJ at 613-617; *Deyong v Shenburn* [1946] KB 227 *per* Du Parcq LJ at 233-234.

misstatements,<sup>15</sup> then extending the scope of the duty of care in *Anns v Merton London Borough Council*.<sup>16</sup> In what became a maligned judgment, Lord Wilberforce explained that it was no longer necessary to develop the duty of care by reference to ‘previous situations in which a duty of care has been held to exist.’<sup>17</sup> He explained that whether a duty existed between the parties had to be approached in two stages:

‘First one has to ask whether, as between the alleged wrongdoer and the person who has suffered damage there is a sufficient relationship of proximity or neighbourhood such that, in the reasonable contemplation of the former, carelessness on his part may be likely to cause damage to the latter ... [Secondly] it is necessary to consider whether there are any considerations which ought to negative, or to reduce or limit the scope of the duty’.<sup>18</sup>

The two-stage test in *Anns* continued to require satisfaction of the neighbour principle and if these elements were demonstrable a *prima facie* duty of care arose. Thereafter, it was for the court to evaluate whether compelling reasons existed to militate against holding a duty was owed or in other ways limit its scope. The test was favourable for claimants because a duty was, in effect, established by demonstrating foresight and proximity and it was left to the defendant to show policy factors militated against a finding of liability. This permitted novel negligence actions to succeed because there was no need to demonstrate an analogy with existing categories of claims.<sup>19</sup> However, Lord Wilberforce’s two-stage approach was not well received and quickly became subject of judicial criticism, with hostility growing over the subsequent decade.<sup>20</sup> The High Court of Australia was first

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<sup>15</sup> *Hedley Byrne v Heller & Partners* [1964] AC 465.

<sup>16</sup> [1978] AC 728.

<sup>17</sup> *Ibid.*, at 751.

<sup>18</sup> *Ibid.*, at 751-752.

<sup>19</sup> For example, the claimants in *Anns* were able to recover for economic loss caused by structural movement. This pro-claimant approach would also have been favourable in claims arising from the nondisclosure of genetic risks to the proband’s family.

<sup>20</sup> For example, *Yuen Kun Yeu v Attorney General of Hong Kong* [1988] AC 175 per Lord Keith at 194: ‘In view of the direction in which the law has since been developing the Lordships consider that for the future it should be recognised that the two stage test in *Anns v Merton London Borough Council* ... is not to be regarded as in all circumstances a suitable guide to the existence of a duty of care.’

to decline to follow the *Anns* test in *Council of the Shire of Sutherland v Heyman*,<sup>21</sup> Brennan J clearly articulating judicial concerns with the two-stage approach:

‘the law should develop novel categories of negligence incrementally and by analogy with established categories, rather than by massive extension of *prima facie* duty of care restrained only by indefinable ‘considerations’ which ought to negative, or to reduce or limit the scope of the duty or the class of persons to whom it is owed.’<sup>22</sup>

The House of Lords was persuaded by Brennan J’s *dicta* when the opportunity arose to reconsider the test for the duty of care in *Murphy v Brentwood District Council*<sup>23</sup> and *Caparo v Dickman*.<sup>24</sup> In both judgments their Lordships approved of the approach of the High Court of Australia<sup>25</sup> and Lord Bridge delivered a speech in *Caparo* that ‘has come to be regarded as the classic exposition of the modern approach to the duty of care’.<sup>26</sup> He said:

‘in addition to the foreseeability of damage ... there should exist between the party owing the duty and the party to whom it is owed a relationship characterised by law as one of “proximity” or “neighbourhood” and that the situation should be one in which the court considers it fair, just and reasonable that the law should impose a duty of given scope on one party for the benefit of the other.’<sup>27</sup>

At first blush, the three-part test from *Caparo* might appear to be a restatement of the two-stage approach from *Anns*. Foreseeability and proximity remain necessary ingredients to establishing a duty of care. Policy considerations also continue to be evaluated via the requirement a duty be fair, just and reasonable. However, the approaches adopt different perspective on duty and, as Lunney and Oliphant explain, the shift

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<sup>21</sup> (1985) 60 ALR 1.

<sup>22</sup> *Ibid.*, at 43-44.

<sup>23</sup> [1991] 1 AC 398.

<sup>24</sup> [1990] 2 AC 605.

<sup>25</sup> In *Caparo*, *ibid.*, Lord Bridge at 618 drew upon ‘the wisdom of the words of Brennan J’.

<sup>26</sup> Lunney, M., Oliphant, K., *Tort Law: Texts & Materials*, 5<sup>th</sup> ed. (OUP: Oxford, 2013), p. 140.

<sup>27</sup> *Caparo*, above, n 24, at 617-618.

‘may aptly be characterised as one between an approach that starts from the presumption of a duty, and requires the invocation of policy factors if the duty is to be negated, and one that starts from a presumption of no duty, and requires the invocation of policy factors if a new duty is to be established.’<sup>28</sup>

The shift from expansion to restriction was also encapsulated by Lord Bridge, who suggested that negligence had moved in a direction of attaching greater significance to analogy as a guide ‘to the existence, the scope and the limits of the varied duties of care the law imposes.’<sup>29</sup> He approved of the High Court of Australia’s preference for incremental development and called for a similar approach to be adopted domestically. This could be seen as precluding (or at least making it very difficult) to prove novel duties exist because there may not be a readily available analogy, although the point is somewhat moot following *Commissioners of Customs and Excise v Barclays Bank Plc.*,<sup>30</sup> where the House of Lords stated that ‘[i]n absence of any touchstone [of liability] ... a court faced with a novel situation must apply the threefold test.’<sup>31</sup> The tort of negligence thus remains flexible and adaptable and extension is possible in absence of analogous case law, providing the three-part test is satisfied. This reflects Lord Macmillan’s statement in *Donoghue* that ‘the categories of negligence are never closed’.<sup>32</sup> Some commentators have argued the law is experiencing a restrictive period;<sup>33</sup> it is perhaps more appropriate to describe the prevailing judicial attitude as one of consolidation and circumspection, whereas the 1970s represented a period of legal trailblazing. Negligence has continued to develop and encompass new liabilities<sup>34</sup> but the pace of change has slowed, particularly in

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<sup>28</sup> Lunney, Oliphant, above, n 26, p. 141.

<sup>29</sup> Caparo, above, n 24, at 618.

<sup>30</sup> [2007] 1 AC 181.

<sup>31</sup> *Ibid.*, per Lord Roger at 53.

<sup>32</sup> *Donoghue*, above, n 9, at 619.

<sup>33</sup> Chico, above, n 4, p. 2.

<sup>34</sup> The decision regarding asbestosis and mesothelioma in *Fairchild v Glenhaven Funeral Services* [2003] 1 AC 32 being a key example, albeit a decisions regarding causation not duty. See also litigation concerning sexual abuse, e.g. *JGE v The Trustees of the Portsmouth Roman Catholic Diocesan Trust* [2012] EWCA Civ 938. The liability of schools has also been extended regarding the failure to recognise dyslexia, see *Phelps v Hillingdon London Borough Council* [2001] 2 AC 619; c.f. *Adams v Bracknell Forest Distric Council* [2005] 1 AC 76 where liability was not extended to illiteracy.



relation to the duty of care. Against the background of a supposedly increasingly litigious society and amid concerns of a ‘compensation culture’,<sup>35</sup> this quiet trickle of development might be characterised as a search for balance between justice and preventing the opening of the proverbial floodgates.<sup>36</sup>

To successfully establish a duty to disclose it is necessary to overcome judicial caution in respect of extending negligence. Thus any duty must be robust, its scope rigorously defined to avoid potential floodgates arguments. A further obstacle in the context of genetics is that the duty is concerned with non-physical injury, which has traditionally not been ‘on the same [legal] footing as physical injury.’<sup>37</sup> Thus, in advance of analysing the elements of a duty to disclose, it is helpful to consider the courts’ attitude to non-physical harm. This chapter therefore considers the development of liability to secondary victims and whether there are any inferences to be drawn with regard to a duty to disclose genetic risks to a patient’s relatives.

### *Duties to Secondary Victims*

The duty of care to secondary victims is an example of expansion in the tort of negligence and reflects Lord Macmillan’s observation in *Donoghue* that the concept of legal responsibility may develop in accordance with altering social conditions and standards.<sup>38</sup> The courts were initially reluctant to allow recovery for psychiatric injury in absence of physical peril or actual harm, but advancements in psychiatry and changes in societal perceptions have resulted in the judiciary becoming more amenable to claims for psychological injury. As Weir explained in 1992, public perception exerts an influence on what constitutes harm. He wrote:

‘There is ... no doubt that the public draws a distinction between the neurotic and the cripple, between the man who loses his concentration and the man who loses his leg. It is widely felt that being frightened is less than being struck ... the duty to avoid injuring strangers is greater than the duty not to upset them. The law has reflected this situation as one would expect, not only by refusing damages for grief

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<sup>35</sup> For a recent analysis of the compensation culture see Lewis, R., ‘Compensation Culture Reviewed: Incentives to Claim and Damages Levels’ (2014) 4 JPIL 209.

<sup>36</sup> A case that exemplifies the difficulties of balancing justice with possible floodgates issue – and in which the House of Lords arguably erred too much on the side of caution – was *Alcock v Chief Constable of South Yorkshire* [1992] 1 AC 310.

<sup>37</sup> Chico, above, n 4, p. 29.

<sup>38</sup> *Donoghue*, above, n 9, at 619.

altogether, but by granting recovery for other psychical harms only late and grudgingly.’<sup>39</sup>

Weir’s point might also be applied to the nondisclosure of genetic risks. It is possible that harm resulting from a lack of knowledge of a risk is perceived as less serious than harm caused by negligent treatment. The liability of doctors failing to disclose of risks to patients suggests nondisclosure does already constitute harm in particular circumstances. Of course, the nondisclosure of risks to blood relations does lie outside the present scope of liability, but psychiatric injury exemplifies that ‘an outcome which was once not a harm can come to be perceived as such.’<sup>40</sup> Despite initial reluctance, the judiciary has gone as far as to acknowledge that ‘psychiatric harm may be far more debilitating than physical harm’<sup>41</sup> and although the courts remain circumspect about extending liability for mental injury,<sup>42</sup> it is no longer accurate to describe their inclination towards recovery for psychiatric injury as grudging.

Although there are similarities between secondary victims and the proband’s blood relatives a note of caution is necessary. Both types of claim involve liability to parties with whom the defendant is proximate because of a relationship with an intermediary party – the primary victim in psychiatric injury, the proband in nondisclosure. However, though the intermediary is determinative of proximity in both situations, there is a significant difference that must be born in mind. Primary victims are persons in a zone of danger and are either physically injured or physically imperiled (or are reasonably perceived to be so by the secondary victim) as a result of the defendant’s negligence. By contrast, the proband is not at risk of harm if genetic information is not disclosed to their blood relations. Despite this distinction, secondary victims are indicative of the courts willingness to uphold a duty of care to third parties in circumstances where harm to those individuals is reasonably foreseeable. The duty of care to secondary victims is thus a useful case study when discussing creation of a duty to disclose genetic risks to persons beyond the traditional therapeutic relationship.

The prevailing attitude to psychiatric injury at the beginning of the twentieth century was summarised in *Dulieu v White*,<sup>43</sup> where Kennedy J said that liability should

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<sup>39</sup> Weir, T., *A Casebook on Tort*, 7<sup>th</sup> ed. (Sweet & Maxwell: London, 1992), p. 88.

<sup>40</sup> Chico, above, n 4, p. 29.

<sup>41</sup> *White v Chief Constable of South Yorkshire* [1999] 2 AC 455 *per* Lord Steyn at 492.

<sup>42</sup> *Grieves v FT Everard & Sons Ltd* [2007] UKHL 39.

<sup>43</sup> [1901] 2 KB 669.

only exist when a claimant experiences ‘a shock that arises from a reasonable fear of personal injury to oneself’.<sup>44</sup> The decision in *Dulieu* was effectively an attempt to exclude liability to individuals who witnessed a traumatic event but were not themselves at risk of being injured. The difficulty with requiring claimants to fear personal injury was recognised by the Court of Appeal in *Hambrook v Stoke Bros*,<sup>45</sup> wherein Atkin LJ (as he then was) explained it

‘would result in a state of law in which a mother, shocked by fright for herself, would recover, while a mother shocked by her children being killed before her eyes, could not’.<sup>46</sup>

*Hambrook* represents the beginnings of a duty to secondary victims but the Court of Appeal provided little exposition of the content and scope of the duty. The House of Lords was provided with an opportunity to address this uncertainty in *Bourhill v Young*,<sup>47</sup> wherein the claimant witnessed the aftermath of a road traffic accident and alleged it caused her to suffer shock and a miscarriage. Their Lordships rejected the woman’s claim because it was not considered foreseeable that an individual of reasonable phlegm would suffer shock in those circumstances, distinguishing *Hambrook* on its facts. The outcome excluded bystanders from the duty expressed in *Hambrook* but, though the duty’s scope was refined, their Lordships did little to explain its content and there was no attempt made to reconcile the cases, though it can be implied that a person of reasonable phlegm would have suffered shock in *Hambrook* as the injured child’s parent.

The decisions in *Hambrook* and *Bourhill* demonstrate the serpentine development of tort law, which has been described by commentators as one step forwards and two steps back.<sup>48</sup> The evolution of liability to secondary victims is a window onto the shifting perspectives that influence development of novel duties of care. To some extent, new duties are dependent upon the constitution of the courts: a judge with expansionist views

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<sup>44</sup> *Ibid.*, at 675.

<sup>45</sup> [1925] 1 KB 141. A mother suffered psychiatric injury after witnessing a driverless lorry careen downhill towards where she knew her children were and, shortly thereafter, hearing that a child fitting the description of her own had sustain an injury.

<sup>46</sup> *Ibid.*, at 157.

<sup>47</sup> [1943] AC 92, HL.

<sup>48</sup> Deakin, S., Johnston, A., Markesinis, B., *Tort Law*, 7<sup>th</sup> ed. (OUP: Oxford, 2012), p. 2.

(or one sympathetic to the claimant) might rule favourably for the injured party, while a more conservative judge might refuse to extend the scope of tort law or take the opportunity to reign in an earlier decision. Development in torts ebbs and flows, shifting from expansion to contraction, as exemplified by *Dulieu*, *Hambrook* and *Bourhill*.

The duty to secondary victims started to stabilise in the 1980s and reached somewhat of a plateau in the 1990s, coinciding with the emergence of a more conservative approach to the duty of care concept. The crucial decisions that shaped the modern approach to secondary victims were *McLoughlin v O'Brian*,<sup>49</sup> *Alcock v Chief Constable of South Yorkshire*<sup>50</sup> and *McFarlane v E. E. Caledonia*.<sup>51</sup> These cases provide an indication of the courts' approach to liability for non-physical injury to third parties and how the limits of such accountability are defined. They are also indicative of the pitfalls that should be avoided when constructing a duty to disclose.

The decision in *McLoughlin* reflected the earlier judgment in *Hambrook* and affirmed that a duty is owed to close relations of those negligently injured by the defendant. The claimant was a woman who suffered severe shock after witnessing the condition of her husband and children in hospital – described as 'distressing in the extreme'<sup>52</sup> – in the aftermath of a road traffic accident. The House of Lords considered that she fell within a class of persons who the law already permitted to recover damages for psychiatric injury, namely those possessing a close tie of love and affection to the injured or deceased party.<sup>53</sup> Lord Wilberforce further added that

'to insist on direct and immediate sight or hearing would be impractical and unjust and that under the aftermath doctrine, one who, from close proximity comes very soon to the scene, should not be excluded.'<sup>54</sup>

It was thus held that the defendant's duty of care extended to individuals who did not directly perceive the traumatic incident but witnessed its aftermath, however its scope was restricted to those claimants in a close relationship with the victim(s). Lord Bridge agreed

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<sup>49</sup> [1983] AC 410.

<sup>50</sup> [1992] 1 AC 310.

<sup>51</sup> [1994] 2 All ER 1.

<sup>52</sup> *McLoughlin*, above, n 49, *per* Lord Wilberforce at 417.

<sup>53</sup> *Ibid.*, at 421-422.

<sup>54</sup> *Ibid.*, at 422.

that the claimant's case was merit worthy and allowed the appeal. But, in contrast to Lord Wilberforce, Lord Bridge was reluctant to define the scope of liability by reference to proximity, perception or consanguinity, arguing that to do so was to 'impose a largely arbitrary limit of liability'.<sup>55</sup> He contended that:

'this is an area of negligence where we should resist the temptation to try yet once more to freeze the law in a rigid posture which would deny justice to some who, in the application of the classic principles of negligence ... ought to succeed, in the interests of certainty, where the very subject matter is uncertain and continuously developing'.<sup>56</sup>

Lord Bridge's statement regarding rigid boundaries applies equally to genetic risks. The law should not refuse to establish a duty to disclose because proximity is not demonstrated by traditional means, i.e. the existence of a doctor-patient relationship. Although a degree of certainty is necessary if healthcare practitioners are to effectively discharge their duty, the tort of negligence also needs to remain flexible in the interests of justice. A duty to disclose, however, can be defined by reference to consanguinity because of the familial nature of genetic risk, thereby may potentially avoid arguments concerning indeterminate liability that apply to secondary victims.

Despite Lord Bridge's reticence, the House of Lords did attempt to freeze the law on psychiatric injury in a 'rigid posture' in *Alcock*, producing mixed results in the long term. *Alcock* was a test case arising from the Hillsborough Stadium disaster in 1989 where a crowd crush during an FA Cup semi-final between Liverpool and Nottingham Forest resulted in 96 deaths and 766 further injuries. The case concerned psychiatric injury sustained by relatives of those who were at the ground. Although Lord Bridge had earlier called for flexibility regarding secondary victims, the House of Lords opted for a conservative approach. Approving the scope of liability Lord Wilberforce applied in *McLoughlin*, which referenced 'the class of persons whose claims should be recognised; the proximity of such persons to the accident; and the means by which the shock is caused',<sup>57</sup> their Lordships dismissed the appeals, concluding no duty arose because of a lack of sufficient proximity between the parties. The main reason for their findings was that none of the claimants has demonstrated a close tie of love and affection with the

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<sup>55</sup> *Ibid.*, at 442.

<sup>56</sup> *Ibid.*, at 443.

<sup>57</sup> *McLoughlin*, above, n 49, at 422.

victims. Though Lord Wilberforce had alluded that a duty arose when a close tie of love and affection existed between claimant and victim in *McLoughlin*, the tie was axiomatic on the facts and did not warrant further consideration. In *Alcock*, the House of Lords considered it a prerequisite to liability and only presumed that a close tie existed between parent-child and spouses. In all other circumstances, the presumption that no close tie existed had to be rebutted. Considering the claim of a man who had lost his brother in the disaster, Lord Ackner explained:

‘The quality of brotherly love is well known to differ widely – from Cain and Abel to David and Jonathan ... [the] claim was not presented upon the basis that there was such a close and intimate relationship between them as gave rise to that very special bond of affection which would make his shock-induced psychiatric injury reasonably foreseeable.’<sup>58</sup>

*Alcock* is a significant example of mercurial judicial attitudes and how negligence can quickly shift. Prior to their Lordships’ decision it was unknown that a close tie of love and affection ‘was a precondition of liability in such cases.’<sup>59</sup> The judgment has been criticised as it was ‘harsh to disallow a claim for not being pleaded in a way that no-one had previously suggested was necessary.’<sup>60</sup> Their Lordships’ decision can also be fairly portrayed as representative of the conservative approach to extending the duty of care that had been building since the late 1980s, albeit at an extreme point on the spectrum.

Though the House of Lords dismissed the claimants’ action, Lord Ackner,<sup>61</sup> Lord Keith<sup>62</sup> and Lord Oliver<sup>63</sup> ‘were prepared to accept that there might be liability [in absence

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<sup>58</sup> *Alcock*, above, n 50, at 406.

<sup>59</sup> Lunney, M., Oliphant, K., above, n 24, p. 346.

<sup>60</sup> *Ibid.*

<sup>61</sup> *Alcock*, above, n 50, at 403: ‘while it may be very difficult to envisage a case of a stranger, who is not actively and foreseeably involved in a disaster or its aftermath, other than in the role of a rescuer, suffering shock-induced psychiatric injury by mere observation of apprehended or actual injury of a third person ... I see no reason in principle why he should not, if in the circumstances, a reasonably strong-nerved person would have been so shocked. In the course of argument your Lordships were given, by way of an example, that of a petrol tanker careening into a school in session and bursting into flames. I would not be prepared to rule out a potential claim by a passer-by so shocked by the scene as to suffer psychiatric illness.’

<sup>62</sup> *Ibid.*, at 397: ‘The case of the bystander unconnected with the victims of an accident is difficult. Psychiatric injury to him would not ordinarily, in my view, be within the range of reasonable foreseeability, but could not perhaps be entirely excluded from it if the circumstances of a catastrophe occurring very close to him were particularly horrific.’

of a close emotional tie] when the accident witnessed by a bystander was particularly horrific.’<sup>64</sup> Strangely, their Lordships did not consider the Hillsborough disaster horrific enough for liability to accrue and avoided providing an explanation as to ‘how any “scales of horror” could be devised, especially given the subjective nature of reactions to such events.’<sup>65</sup> The implication is that their Lordships were attempting to leave themselves room to maneuver in the event that a ‘horrific’ disaster occurred leading to claims by bystanders, yet the introduction of this loophole was inconsistent with the remainder of the *Alcock* judgment.

This inconsistency was recognised by the Court of Appeal in *McFarlane*, a case arising from the *Pipia Alpha* disaster in July 1988, when a series of explosions destroyed a North Sea oil and gas rig killing 167 of the 229 crewmen aboard. The claimant had been aboard a support ship that went to assist in rescue and firefighting operations, suffering psychiatric injury as a consequence of his experiences before he was airlifted to safety. The Court of Appeal dismissed his claim because he was neither a primary victim, as he had not been physically imperiled, nor a secondary victim because he lacked a close tie of love and affection with those aboard the *Alpha*. It was considered extending liability to bystanders ‘ran counter to the general thrust of *Alcock* and would present practical problems since reactions to horrific events are subjective and variable.’<sup>66</sup>

Liability to secondary victims is a useful litmus test when exploring the possibility of a duty to disclose genetic risks to the proband’s blood relations. First, it is proof that ‘an outcome which was once not considered a harm can come to be perceived as such.’<sup>67</sup> Second, it demonstrates that the judiciary is willing to extend the scope of negligence as our understanding of human biology and psychology develops. Genetic technology and our understanding of the human genome and its role in disease are advancing rapidly. Liability for psychiatric injury demonstrates a willingness to accept novel claims as medical knowledge and psychiatry develop, thus it is arguable the courts will grow

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<sup>63</sup> *Ibid.*, at 416: ‘I would not exclude the possibility envisaged by my noble and learned friend, Lord Ackner, of a successful claim, given circumstances of such horror as would be likely to traumatise even the most phlegmatic spectator, by a mere bystander.’

<sup>64</sup> Lunney, M., Oliphant, K., above, n 24, p. 346.

<sup>65</sup> *Ibid.*

<sup>66</sup> Peel, E., Goudkamp, J., *Winfield & Jolowicz on Tort*, 19<sup>th</sup> ed. (Sweet & Maxwell: London, 2014), p. 232. It is difficult to understand why a petrol tanker careening into a school is any more horrific than Hillsborough or *Pipa Alpha*; for further discussion, see Oughton, D., Lowry, J., ‘Liability to Bystanders for Negligently Inflicted Psychiatric Harm’ (1995) 46 NILQ 18.

<sup>67</sup> Chico, V., above, n 4, p. 29.

increasingly receptive to claims arising from genetic technology as science and medicine advance. In 1992, Weir described recognition of psychiatric injury as grudging, but in the two decades since the House of Lords decided *Alcock* the courts have become more open to claims for psychiatric harm. The House of Lords has even acknowledged that

‘there is no rigid distinction between body and mind ... a recognisable psychiatric illness results from an impact on the central nervous system. In this sense therefore there is no qualitative difference between physical and psychiatric harm. And psychiatric harm may be far more debilitating than physical harm.’<sup>68</sup>

If there is no rigid distinction between body and mind then it may also be argued that the same is true of the physical body and genetics: the nondisclosure of a genetic risk ultimately interferes with the physical wellbeing of the individual.

Finally, the development of a duty to secondary victims demonstrates a willingness to uphold liability to third parties where it is in the interests of justice. Despite the dismissal of the claims in *Alcock*, the House of Lords did create a duty to individuals who were not traditionally proximate to the defendant, but became proximate because of a relationship to the victim.<sup>69</sup> There is a similarity in this respect with a duty to disclose genetic risks, as proximity is determined by consanguinity. The foundations of liability for genetic nondisclosure are therefore already present in negligence. A duty to disclose does not represent a wholesale departure from existing principles of liability but builds upon them. If the courts are willing to accept a duty arises because of an emotional tie with victims of the defendant’s negligence, it is not radical to suggest the courts may be receptive to liability predicated upon genetic links. Because descendants of a common gene pool share genes, commonality is greatest within the nuclear family, thus the risk of indeterminate liability does not arise, unlike in claims flowing from circumstances like those in *Alcock*.

It is therefore possible to suggest that while the duty to disclose would represent an extension to the duty of care it is not a radical departure from current models of liability. The question is whether – given the conservative approach to duty highlighted above – the

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<sup>68</sup> *White v Chief Constable of South Yorkshire* [1999] 2 AC 455 *per* Lord Steyn at 492.

<sup>69</sup> The rigid posture affected in *Alcock* also appears to have been relaxed somewhat, see for example: *AB & Others v Leeds Teaching Hospital* [2005] QB 506; *Gali-Atkinson v Seghal* [2003] All ER (D) 341 (Mar); *Walters v North Glamorgan NHS Trust* [2003] PIQR P16; *Tredget & Tredget v Bexley Health Authority* [1994] Med LR 178.



judiciary are willing to create a duty to disclose, particularly considering it will require the courts to either acknowledge a new head of damage or reinterpret existing types of harm.

### *Protecting Interests or Remediating Harms*

The changeable attitude of the courts to extending negligence to novel types of injury during the 20<sup>th</sup> century suggest it is not a foregone conclusion that a duty to disclose will be accepted or rejected. The question is whether such can be established using the *Caprao* test, which remains the threshold for new duties of care. However, before undertaking a substantive analysis of the elements of the three-stage test in the genetic context, it is important to return to the earlier posed question: what is the underlying purpose of a duty to disclose?

On the one hand, a duty could be created to vindicate a claimant's interest in knowing about the proband's genetic risks; on the other, it could recognise and remedy harm caused by nondisclosure. The second of these permutations follows the traditional approach of negligence, although the distinction is to some extent artificial because negligence 'is not actionable unless it involves the invasion of a legally protect interest.'<sup>70</sup> An invasion of an interest is necessary but a duty that recognises and remedies harm also requires that the claimant is foreseeably injured. Secondary victims provide an illustration: the claimant must show more than an interference with their interest in mental integrity, they must also prove they are suffering from a recognised psychiatric illness.

If a duty is focused on vindicating the claimant's interest, liability accrues when the relevant interest has been frustrated. For example, in actions for battery or false imprisonment it is not necessary for the defendant to cause harm to the claimant, it is sufficient that their actions infringe the interest protected by those torts. If the purpose of a duty to disclose is to protect the claimant's interest in genetic information, then the duty will be breached by the decision not to disclose. In contrast, a duty concerned with remedying harm would require the nondisclosure to harm the claimant before liability would accrue.

The immediate difficulty with a duty that protects an interest is that a potential conflict arises with the proband's interest in confidentiality. Disclosure would need careful balancing against confidentiality and would require the support of a countervailing public interest. It was argued in the proceeding chapter that the most compelling justifications for disclosing genetic information flow from a public interest in preventing harm and Art 2 ECHR. A duty concerned solely with the frustration of an interest in genetic information

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<sup>70</sup> *Palsgraf v Long Island Railway Co* 59 ALR 1253 (New York Court of Appeals, 1928) *per* Cardozo J at 99.

would not fall within these justifications for breaching confidentiality and data protection. Furthermore, an interest-based duty could lead to a situation where the confidentiality of the patient is subservient to the interests of their blood relations. Confidentiality allows disclosure where there is a ‘countervailing public interest which favours disclosure’,<sup>71</sup> but it is difficult to reconcile protecting a familial interest in genetic information with public interests in harm or the right to life. Broader public interests may offer some measure of support to an interests-based duty but, as discussed previously, broader interests can encounter a problem in that other means for advancing the public interest exist. A duty focused on harm arising because of nondisclosure is (potentially) consistent with the public interest in preventing harm and Art 2 ECHR and thus a justifiable breach of confidentiality.

A traditional approach to duty focused on harm is favoured here but whichever permutation of duty is preferred, a fundamental requirement is that the claimant demonstrate ‘a wrong to herself, i.e., a violation of her own right.’<sup>72</sup> The interest being infringed must be legally recognised because where ‘claims relate to the defeating of interests which are not legally recognised harm in negligence, they are currently largely likely to meet with rejection.’<sup>73</sup> A duty protecting an interest in genetic information therefore requires courts to, firstly, recognise that interest and, secondly, accept that frustration of that interest is actionable in tort. Working within the traditional framework of duty, harm consequential to nondisclosure can be reconciled with interests already protected in negligence.

The interest in bodily integrity includes an interest in mental integrity because – *per* Lord Steyn in *White* – mental and physical injury are indivisible. The same logic can be applied to one’s health. If the wellbeing of a claimant is compromised by negligence – say, through exposure to toxins – the harm constitutes an interference with bodily integrity. In the context of genetics, if a risk of disease is not disclosed and disease eventuates – and either a cure or preventative treatment was available – then the nondisclosure can be characterised as interfering with the claimant’s bodily integrity. Knowing about genetic risks may therefore be reconciled with an interest recognised in negligence. If this view is correct, the core themes of the duty also coincide with the public interests justifying derogation from confidentiality and data protection.

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<sup>71</sup> *Attorney General v Guardian Newspapers* (No. 2) [1990] 1 AC 109, HL, *per* Lord Goff at 282.

<sup>72</sup> *Palsgraf*, above, n 70, at 100.

<sup>73</sup> *Chico*, above, n 4, p. 16.

If it is demonstrable that nondisclosure causes foreseeable harm, a duty can be constructed with recognition of harm at its core, a formulation consistent with the role of negligence in setting standards for persons whose carelessness may cause injury. Furthermore, the recognition of harm provides succinct justification for breaching doctor-patient confidentiality and is consistent with the GMC guidelines on confidentiality, which advise disclosures can be made when there exists a risk of foreseeable harm to a non-patient.<sup>74</sup> The proposed duty would therefore integrate elements of professional guidance, the crucial distinction being that the duty would create an obligation; the GMC's guidelines do not.

A duty to disclose can thus be formulated in a manner consistent with the traditional foci of negligence, although a possibility remains that the courts could accept an interests-based duty instead. The probability of this outcome is low, however. Duties to protect rights and interests do exist within the UK's legal system but they are not prevalent in negligence. This question is whether a system built around recognition and remedying of harms can be used as a foundation for a duty vindicating an interest. A duty could arise through application of human rights legislation, which has become somewhat influential within domestic law.<sup>75</sup> However, the extent of its influence on the development of negligence is open to debate. The most prominent human right insofar as negligence is concerned is arguably Art 6 ECHR, as it guarantees the right to a fair trial and prevents the creation of blanket immunities for public authorities and services.<sup>76</sup> Art 6 places a duty upon the court to act compatibly with convention rights and this duty is set out in the Human Rights Act 1998. It is unusual for human rights to achieve recognition through common law duties, although the duty on the court means human rights are capable of influencing common law decisions. Thus it may be that claimants argue knowing about genetic risks is an aspect of their Art 8 right to respect for private and family life or, in extreme circumstances, potentially their Art 3 right to freedom from inhumane and degrading treatment,<sup>77</sup> but such interests are not protected in negligence.

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<sup>74</sup> GMC, *Confidentiality: guidelines for doctors* (London, 2009), paragraph 53.

<sup>75</sup> For example, *Ghaidan v Godin-Mendoza* [2004] UKHL 30 and *A & Others v Secretary of State for the Home Department* [2004] UKHL 56

<sup>76</sup> For an example of this type of immunity, see *Hill v Chief Constable of West Yorkshire* [1988] 2 WLR 1049. Blanket immunity to negligence actions was held to amount to breach of the ECHR in *Osman v UK* [1988] EHRR 101. The application of Art 6 was also considered in *Z v UK* [2001] 2 FLR 612, although no breach was upheld.

<sup>77</sup> Both Art 8 and Art 3 arose in *RR v Poland* [2011] ECHR 828, although here the issue was access to genetic testing during pregnancy, not disclosure of genetic testing.

This is not to say that interests-based duties have not arisen in negligence and the argument in favour of a duty protecting the interests of blood relations may find support in *Reeves v Commissioner of the Police of the Metropolis*.<sup>78</sup> The case arose as a consequence of a man committing suicide in police custody, despite the attending officers being forewarned that he may attempt suicide. An assessment conducted shortly after the man arrived at the police station indicated he was suffering neither psychiatric illness nor clinical depression, but officers were nonetheless instructed to observe him frequently. Following one check, the flap in his cell door was inadvertently left open and the man tied his shirt through the spyhole on the exterior of the door and hung himself.

The claimant – the administratrix of the deceased’s estate – argued that the police had been negligent in their actions. The defendant conceded that a duty was owed to the man while he was in custody, which meant the House of Lords was not required to explore the content of the police’s duty to detainees. The focus was instead on whether suicide constituted a *novus actus interveniens*. Had their Lordships assessed the content of the duty to detainees it is suggested they would have struggled to reconcile it with traditional principles of negligence. A duty arguably existed in the circumstances because of the rights of the detainee, not the harm caused by the defendant. The duty cannot be reconciled with the man’s interest in bodily integrity because ‘the defendant’s action was not wrongful relative to that right.’<sup>79</sup>

For a duty to exist between two parties there must be a correlation between the negligent act and the frustrated interest because the claimant cannot recover ‘unless the defendant’s action is a wrong in relation to that right.’<sup>80</sup> In plain terms, the interest a duty vindicates must be the interest the defendant negligently frustrates. Thus in *Reeve* the duty cannot flow from an interest in bodily integrity because the negligence did not interfere with that particular interest. A starker illustration can be found in *Palsgraf v Long Island Railway Co*. Here the action was based in the claimant’s interest in bodily integrity, which, it was argued, the defendant infringed through their negligent handling of box of fireworks that fell onto the tracks and exploded. The resultant shockwave caused a set of scales at the far end of the station to fall from their mount and strike the claimant. The claimant’s ‘right to her bodily security was not disputed’, but it was concluded that ‘the defendant’s action was not wrongful relative to that right’, because the negligent act

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<sup>78</sup> [2000] 1 AC 360.

<sup>79</sup> Weinrib, E., ‘The Disintegration of Duty’ in Madden, M. (ed.), *Exploring Tort Law* (Cambridge University Press: Cambridge, 2005), p. 156.

<sup>80</sup> *Ibid.*

actually infringed another's interest in property and not the claimant's bodily integrity.<sup>81</sup> The absence of correlativity between the frustrated interest and the harm meant that no duty was owed to the claimant.

In *Reeves*, the negligence of the officers in leaving the cell door flap open did not physically threaten the detainee. His interest in bodily integrity was therefore not infringed. A better explanation of the basis of the police's duty is the detainee's Art 2 right to life, since because he was a known suicide risk the negligence of the officers constituted a failure to safeguard his Art 2 right. The House of Lords and the Court of Appeal both appear to support this interpretation as they conclude that since officers were aware of the risk of suicide, it was a risk they were under a duty to mitigate and, therefore, in leaving the flap open and providing the man with a means to commit suicide, had failed to discharge their duty. The courts, it would seem, impliedly accepted a duty with the purpose based on protecting the detainee's interest rather than remedying a harm.

The subsequent decision in *Orange v Chief Constable of West Yorkshire*<sup>82</sup> supports an interest-based interpretation of the duty in *Reeves*. *Orange* also concerned the suicide of a detainee, however, the facts diverged from those in *Reeve* because the police were not forewarned that the man was a suicide risk. The Court of Appeal concluded that the defendants had taken all reasonable precautions, taking account of the higher rate of suicides among remand prisoners, and dismissed the claim. The actions of the police had not infringed the detainee's Art 2 right and a lack of forewarning meant that there was no correlativity because the defendant's actions did not infringe the claimant's interests in the circumstances. As Latham LJ summarised, 'the special and unusual duty [in *Reeves*] is one which is only owed where the authorities know, or ought to know, of a suicide risk in an individual prisoner's case.'<sup>83</sup>

This brief analysis demonstrates a potential within negligence to recognise duties concerned with vindicating an interest as opposed to remedying harm. However, as was noted in *Orange*, these duties are exceptional. The interest protecting by the duty in *Reeves* was also an immutable right. An interest in knowing about genetic risks is not immutable, nor is it legally recognised at present. A question therefore remains about whether this interest could be the basis of a *Reeves*-type duty. The courts conservative approach to the duty of care suggests that it is unlikely, but the decision in *Reeves*

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<sup>81</sup> *Ibid.*

<sup>82</sup> [2001] EWCA Civ. 611.

<sup>83</sup> *Ibid.*, at 47.

demonstrates that negligence is capable of vindicating interest, so it cannot be completely ruled out.

The predominant focus in negligence remains the remedying of harms. This thesis examines nondisclosure of genetic risks within this traditional framework and does not argue in favour of an interests-based approach to duty. A person's interest in knowing about genetic risk is not at present considered a fundamental interest. Thus the courts are unlikely to accept frustration of such an interest as a basis of a duty of care. The analysis here reflects this improbability.

Situating a duty to disclose with the traditional negligence framework of recognising and remedying of harms, however, raises a fundamental question about what the harm is within the context of nondisclosure. This question is significant and it is one to which this thesis will return to in chapter four.

### *The Common Law and Disclosure of Information – The Duty to Patients*

Situating a duty to disclose within the traditional harm focused framework of negligence provokes the question, how has negligence thus far grappled with issues relating to disclosure? There are two strands of case law that are relevant when answering the question. The first relates to disclosure within the doctor-patient relationship. The second concerns disclosure of risk to third parties. The immediate focus is case law involving patients; case law involving third parties is examined in the subsequent sections.

A patient's fundamental grievance when bringing an action regarding a failure to disclose can be summarised as: '[y]ou did not inform me of the risk which has eventuated; but for your failure, I would not have consented to the procedure; you have failed in your duty of care and, as a result, I have sustained injury.'<sup>84</sup> Consent is the interest at the core of this strand of claim. Jackson explains this is because the tort of negligence is:

'incapable of recognising a patient's inherent interest in material information, and so informed consent becomes a route for patients to seek financial compensation for unfortunate but blameless medical outcomes.'<sup>85</sup>

The action, however, does not flow from a lack of consent, which would create a claim in battery.<sup>86</sup> Instead, it is a result of negligence on the part of the clinician when obtaining the

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<sup>84</sup> Mason, J.K., Laurie, G.T., *Mason & McCall-Smith's Law and Medical Ethics*, 9<sup>th</sup> ed. (OUP, Oxford: 2013) p. 106.

<sup>85</sup> Jackson, E., *Medical Law: Texts, Cases and Materials*, 3<sup>rd</sup> ed. (OUP, Oxford: 2013), p. 300.

consent. Specifically, it is the failure to disclose certain risks which would have affected the patient's giving of consent had they known about them. A problem with this type of claim is that

‘Doctors who exercised all due care and skill in the performance of an operation will be found liable for the consequences of an accident which they could have done nothing to prevent just because their pre-operation disclosures were inadequate.’<sup>87</sup>

The difficulty for the courts is deciding whether or not the patient was sufficiently informed in the circumstances and ‘[t]here has been a significant amount of uncertainty over the years about the precise ambit of a doctor's duty of disclosure and how it is to be judged’.<sup>88</sup> One pressing issue with an *ex post facto* assessment of disclosure is that it could be ‘coloured by hindsight’,<sup>89</sup> with the court, in effect, being asked to rule on the credibility of the claimant.

The sufficiency of disclosure is also closely linked with the doctrine of informed consent. An in-depth analysis of informed consent is beyond the scope of this thesis, suffice to say the doctrine was rejected by the courts in *Sidaway v Board of Governors of the Bethlem Royal Hospital* as forming ‘no part of English law’,<sup>90</sup> but commentators argue that it is ‘now part of the lore of medical ethics and its repetition among even the highest ranks of the judiciary means that we must accept it’.<sup>91</sup> Mason and Laurie suggest that following the House of Lords decision in *Chester v Afshar*<sup>92</sup> ‘the question is no longer, “is the doctrine of informed consent coming to the United Kingdom?” but rather “what can we do to improve upon the American model?”’<sup>93</sup> The decision in *Chester* may put domestic

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<sup>86</sup> As in *Re B (Consent to Treatment: Capacity)* [2002] 1 FLR 1090.

<sup>87</sup> Jackson, above, n 85, p. 300-301.

<sup>88</sup> Heywood, R., ‘Medical disclosure of alternative treatments’ (2009) CLJ 68(1) 30-32, p. 30.

<sup>89</sup> Chico, above, n 4, p. 97, p. 137.

<sup>90</sup> [1984] 1 All ER 1018, CA, *per* Dunn LJ at 1030.

<sup>91</sup> Mason, Laurie, above, n 84, p. 108, referring to the judgment of Lord Steyn in *Chester v Afshar* [2005] 1 AC 134 at 14 where his Lordship stated: ‘Surgery performed without the informed consent of the patient is unlawful. The court is the final arbiter of what constitutes informed consent.’

<sup>92</sup> [2005] 1 AC 134.

<sup>93</sup> Mason, Laurie, above, n 84, p. 120.

law within touching distance of a doctrine of informed consent, but it is important to note that the decision related to causation, not breach, therefore any inferences drawn regarding informed consent must be drawn cautiously.

Consent and disclosure are symbiotic elements of the doctor-patient relationship, however, this thesis is not concerned with issues of informed consent. The focus here is the scope the duty of disclosure to patients in English law, particularly what should be disclosed and when that disclosure should be made.

The duty of disclosure first arose in *Bolam v Friern Hospital Management Committee*,<sup>94</sup> although the judgment is rather more famous for establishing the ‘responsible body’ test for breach of duty in cases of professional and medical negligence. The issue in *Bolam* regarding disclosure was whether the clinician had been negligent in not disclosing the risks of electroconvulsive therapy (ECT). McNair J drew attention to whether or not sufficient information had been provided to the claimant in his direction to the jury, explaining they had to decide whether in adopting a practice of saying very little and waiting for questions from the patient, ‘they were falling below a proper standard of competent professional opinion ... of whether or not it is right to warn.’<sup>95</sup> McNair J went on to explain that the jury may find that:

‘when a doctor is dealing with a mentally sick man and has a strong belief that his only hope is submission to electroconvulsive therapy, the doctor cannot be criticised if he does not stress the dangers, which he believed to be minimal’.<sup>96</sup>

The direction implied that clinicians were not negligent when they were acting in the patient’s best interest, providing that those actions were consistent with ‘a responsible body of medical opinion.’<sup>97</sup> Disclosure to patients is therefore subject to the same threshold as other types of medical negligence and ‘any argument as to what needs to be disclosed ... hinges upon whether or not the *Bolam* principle applies.’<sup>98</sup> McNair J, in his direction to the jury, appeared to favour a paternalistic approach to information disclosure:

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<sup>94</sup> [1957] 2 All ER 118.

<sup>95</sup> *Ibid.*, at 124.

<sup>96</sup> *Ibid.*

<sup>97</sup> *Ibid.*, at 122.

<sup>98</sup> Mason, Laurie, above, n 84, p. 112.



if a clinician believed it was in the best interests of their patient to withhold particular details, they could not be criticised for doing so.

The *Bolam* approach to disclosure was adopted in subsequent cases,<sup>99</sup> but these invariably dealt with alleged batteries or other types of medical negligence in conjunction with arguments of insufficient disclosure. What the patient ought to be told was modeled paternalistically and no breach of duty existed providing the level of disclosure was consistent with the views of a responsible body of medical opinion.

The House of Lords were finally given an opportunity to evaluate the duty of disclosure on its own merits in *Sidaway v Bethlem Royal Hospital*.<sup>100</sup> The case concerned a failure to disclose a (statistically slight) risk of spinal injury and was an opportunity to reconsider the role of *Bolam* in defining what constituted adequate disclosure. In the Court of Appeal, Donaldson MR strongly asserted that ‘the definition of the duty of care is not to be handed over to the medical or any other profession’ as it was ‘a matter for the law and the courts.’<sup>101</sup> Browne-Wilkinson LJ was also skeptical about the role of the medical profession in determining the standard of care regarding medical disclosure, arguing that ‘the assumption of the role of advisor, whether or not such advice involves any special skill or judgement, carries with it the duty to disclose material or unusual risks.’<sup>102</sup> However, despite notable reservations, he eventually conceded that ‘there are good grounds for holding that in relation to doctors the duty to disclose risks should be approached on a different basis from that applicable to ordinary professional men’.<sup>103</sup> Donaldson MR also accepted ‘the *Bolam* test as the primary test of liability for failing to disclose sufficient information to the patient’.<sup>104</sup> The House of Lords were less critical of *Bolam*, with only Lord Scarman arguing that such cases should be decided by reference to ‘whether in the circumstances ... a reasonable person in the patient’s position would be likely to attach significance to the risk.’<sup>105</sup> On the role of *Bolam*, he said that he found ‘the implications of this view of the law ... disturbing’ as it left ‘the determination of a legal

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<sup>99</sup> E.g. *Chatterton v Gearson & Another* [1981] 1 All ER 257, *Hills v Potter* [1983] 3 All ER 716.

<sup>100</sup> [1984] QB 493.

<sup>101</sup> *Ibid.*, at 513.

<sup>102</sup> *Ibid.*, at 520.

<sup>103</sup> *Ibid.*, at 521.

<sup>104</sup> *Ibid.*, at 513.

<sup>105</sup> [1985] AC 871 at 889.

duty to the judgement of doctors.’<sup>106</sup> Lord Diplock reached a conclusion at the other extreme, stating that deciding when a patient

‘should be voluntarily warned and the terms in which such a warning, if any, should be given ... is as much an exercise of professional skill and judgement as any other part of the doctor’s comprehensive duty of care to the individual patient ... The *Bolam* test should be applied.’<sup>107</sup>

Lord Bridge (with whom Lord Keith agreed) also accepted that ‘a decision [about] what degree of disclosure of risks is best calculated to assist a particular patient make a rational choice ... must primarily be a matter of clinical judgement.’<sup>108</sup> Lord Templemen agreed, stating where a doctor conscientiously endeavoured to explain the arguments for and against a major operation ‘the court will be slow to conclude the doctor has been guilty of a breach of duty ... merely because the doctor omits some specific item of information.’<sup>109</sup>

The decision in *Sidaway* perpetuated the paternalistic approach to risk disclosure. What should be disclosed remained a matter of clinical judgement, irrespective of the patient’s wants or wishes. Lord Bridge and Lord Templemen did, however, accept that *Bolam* was not a panacea for liability. Lord Bridge explained:

‘the judge might in certain circumstances come to the conclusion that disclosure of a particular risk was so obviously necessary to an informed choice on the part of the patient that no reasonably prudent medical man would fail to make it.’<sup>110</sup>

Lord Templemen said:

‘the court must decide whether the patient has suffered harm from a general danger inherent in the operation or from some special danger. In the case of a general danger the court must decide whether the information afforded to the patient was

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<sup>106</sup> *Ibid.*, at 882.

<sup>107</sup> *Ibid.*, at 895.

<sup>108</sup> *Ibid.*, at 900.

<sup>109</sup> *Ibid.*, at 903.

<sup>110</sup> *Ibid.*, at 175.

sufficient to alert the patient to the possibility of serious harm of the kind in fact suffered.’<sup>111</sup>

It is plain from the judgments in *Sidaway* that elements the Court of Appeal and House of Lords were uncomfortable with applying *Bolam* to cases involving information disclosure, yet notwithstanding these reservations it was confirmed as the appropriate threshold for claims regarding the nondisclosure of risks to patients. Despite the impression of unease in *Sidaway* it is noteworthy that ‘the ranks continued to be closed whenever the [*Bolam*] principle was directly questioned.’<sup>112</sup> However, in late 1990s and into the new millennium the analysis of nondisclosure shifted from the perspective of the clinician towards a more patient orientated standard where ‘rigid adherence to the *Bolam* standard is no longer the approach’.<sup>113</sup>

In *Pearce v United Bristol Healthcare NHS Trust*<sup>114</sup> the defendant failed to disclose a statistically slight risk of foetal death to an overdue mother, who had expressed a desire to either induce birth or undergo caesarian section. The defendant did, however, cite the risks involved in inducing labour and the lengthy recovery period associated with caesarians. Sadly, the child died *in utero* as a consequence of the delayed birth and the claimant alleged the doctor was negligent in not disclosing the 0.1 to 0.2 per cent risk associated with the delay. The Court of Appeal dismissed her claim, ‘endorsed *Sidaway* as the law and accepted *Bolam* as the relevant test’<sup>115</sup> but, as Jackson highlights, ‘did appear to move a little closer to the “reasonable patient” test’.<sup>116</sup> Delivering the judgment of the court, Lord Woolf MR said:

‘if there is a significant risk which would affect the judgement of a reasonable patient, then in the normal course it is the responsibility of a doctor to inform the

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<sup>111</sup> *Ibid.*, at 903.

<sup>112</sup> Mason, Laurie, above, n 84, p. 114.

<sup>113</sup> *Ibid.*, p. 116. See also *Smith v Tunbridge Wells Health Authority* [1994] Med LR 334; *McAllister v Lewisham & North Southwark Health Authority* [1994] 5 Med LR 343; *Newell v Goldenburg* [1995] 6 Med LR 371; *Lybert v Warrington Health Authority* [1996] 7 Med LR 71. C.f. *Newbury v Bath District Health Authority* (1999) BMLR 138.

<sup>114</sup> [1995] 1 PIQR 53.

<sup>115</sup> Mason, Laurie, above, n 84, p. 117.

<sup>116</sup> Jackson, above, n 85, p. 276.

patient of that significant risk, if the information is needed so that the patient can determine for him or herself as to what course he or she should adopt.’<sup>117</sup>

However, Lord Woolf’s statement was at odds with the ultimate conclusion in *Pearce*<sup>118</sup> and though it ‘appears to indicate a more robust commitment to the patient’s right to information’,<sup>119</sup> in answering the question ‘significant to whom?’, Lord Woolf ‘appeared to rely upon the *doctors*’ judgement of whether the risk was “significant”, and not Tina Pearce’s own assessment of whether the risk was sufficiently material that it would have affected her decision to accept medical advice and proceed to a natural birth.’<sup>120</sup> Despite this Pearce is seen as taking a step back from *Bolam*. In the subsequent decision of *Wyatt v Curtis*,<sup>121</sup> Sedley LJ explained that Lord Woolf’s formulation refined Lord Bridge’s test by recognising that

‘what is substantial and what is grave are questions on which the doctor’s and patient’s perception may differ, and in relation to which the doctor must therefore have regard to what may be the patient’s perception.’<sup>122</sup>

In *Chester v Afshar*,<sup>123</sup> Lord Steyn approved of Lord Woolf’s approach, stating that in ‘modern medical law paternalism no longer rules and a patient has a *prima facie* right to be informed by a surgeon of a small, but well established risk of serious injury as a result of

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<sup>117</sup> *Pearce*, above, n 114, at 59.

<sup>118</sup> *Ibid.*, at 59: Lord Woolf states ‘as to what would have been the consequences if she had been told of this particularly small risk, it is difficult to envisage ... [it is] my conclusion that, in so far as was possible for this court to make an assessment of this, the inference is that if Mrs. Pearce had been able to understand what she had been told about the increased risk, her decision would still have been to follow, reluctantly, the advice of the doctor’. This conclusion was reached despite the claimant’s unwavering assertions during cross-examination – to which the court had access – that she would *always* have opted for a caesarian section because it bore no increased risk to her child.

<sup>119</sup> Jackson, above, n 85, p. 277.

<sup>120</sup> *Ibid.*

<sup>121</sup> [2003] EWCA Civ. 1779. The case concerned a failure to disclose a risk of foetal abnormality after the mother contracted chicken pox.

<sup>122</sup> *Ibid.*, at 16.

<sup>123</sup> [2004] UKHL 41. The case involved a slight risk of nerve damage, comparable to the risk of paralysis in *Sidaway*.

that surgery.’<sup>124</sup> The rejection of paternalism as a ruling principle implies a shift towards a patient oriented assessment of risk disclosure. This is supported by the judgment of Lord Hope, who felt that the purpose of disclosure was to engender self-determination. He explained:

‘the [patient’s] right to make the final decision and the duty of the doctor to inform the patient if the treatment may have special disadvantages or dangers go hand in hand ... The function of the law is to protect the patient’s right to choose ... it must ensure that the duty to inform is respected by the doctor.’<sup>125</sup>

The decision in *Chester* may represent an endorsement of a patient oriented approach to disclosure in the doctor-patient relationship, but the focus of the case was causation and not breach, thus any inferences must be cautiously drawn. The indication, however, is that the courts are prepared to engender liability where information is withheld and have gone as far as upholding liability where clinicians have failed to disclose alternative treatments.

In *Birch v University College London Hospital NHS Foundation Trust*,<sup>126</sup> the patient suffered a stroke as a result of a cerebral catheter angiogram, which was conducted to discern whether the patient had a posterior communicating artery aneurysm. The angiogram was an invasive procedure and had a slight risk of a stroke, yet an MRI offered an alternative method of diagnosis without such risk. The defendant was negligent for not disclosing the risks and alternative procedure available because ‘even though one [the angiogram] was thought to be slightly more effective than the other at ruling out a potentially serious condition, they both broadly could have reached a similar diagnosis.’<sup>127</sup> This sensibly means that while a clinician owes a duty to disclose alternative elective treatments they would not have to do so in all circumstances, nor disclose ineffective alternatives; the gist of the duty is that patients should be provided with information about realistic alternatives to the treatment proposed with lower risk factors, enabling the patient to choose whether or not to accept the higher risk.

Although a first instance decision, *Birch* suggests that the duty of disclosure is moving away from the paternalism of the *Bolam* test, with the question ‘what should be

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<sup>124</sup> [2005] 1 AC 134 at 143.

<sup>125</sup> *Ibid.*, at 190.

<sup>126</sup> (1999) 48 BMLR 118.

<sup>127</sup> Heywood, above, n 88, p. 31.

disclosed?’ being assessed from a patient oriented perspective. The scope of the duty therefore appears to reflect the depth of information necessary for self-determination in any given circumstance. This is much broader than a duty to disclose genetic risks to family members, which is concerned with preventing harm. The duty to patients is focused on matters of autonomy and self-determination.

#### *A Duty to Disclose to Third Parties*

There is a paucity of case law on the complexities of genetic information. The domestic courts have, however, limited experience of a duty to disclose risks to third parties. This is a stark contrast to US jurisprudence, which has tackled the issue of disclosure to third parties and, to some extent, the familial entanglements involving genetic information. But though it has upheld liability to parties beyond the doctor-patient relationship, American tort law has not devalued the importance of the clinical obligation of confidentiality.<sup>128</sup> US case law therefore provides a useful steer when evaluating how English tort law could recognise a duty to disclose genetic risks. For this reason, it is important to briefly examine the key decisions from the US judiciary.

#### *US Jurisprudence*

The duty to disclose to parties beyond the therapeutic relationship flows from the seminal judgment of the Supreme Court of California in *Tarasoff v The Regents of the University of California*,<sup>129</sup> which concerned the murder of the claimant’s daughter by her ex-lover, a former psychiatric patient of the defendants. During the course of his treatment, the patient had on numerous occasions communicated to his psychiatrists that he intended to kill the victim upon release, yet no attempt was made to warn the victim of the threat the patient posed. The Supreme Court of California was unsympathetic to the defendants and upheld a duty to the victim, Justice Tobriner stating:

‘When a therapist determines, or pursuant to the standards of his profession should determine, that his patient presents a serious danger of violence to another, he incurs an obligation to use reasonable care to protect the intended victim against such danger. The discharge of this duty may require the therapist to take one or more various steps, depending on the nature of the case. Thus it may call for him to warn the intended victim or others likely to apprise the victim of the danger, to

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<sup>128</sup> See *People of the State of New York v Robert Bierenbaum*, Indictment #8295/99.

<sup>129</sup> 529 P 2d 55 (Cal. 1974), 551 P 2d 334 (Cal. 1976).

notify the police, or to take whatever other steps are reasonably necessary under the circumstances ... once a therapist does in fact determine, or under applicable professional standards reasonably should have determined, that a patient poses a serious risk of danger of violence to others, he bears a duty to exercise reasonable care to protect the foreseeable victim of that danger.’<sup>130</sup>

A duty of care arose because the non-patient victim was an identifiable third party whose jeopardy arose from a risk that was known to the defendants. It was breached because the psychiatrists failed to disclose the threat to either the victim or those likely to warn her of the risk. The court rejected an argument that the defendants’ obligation of confidentiality prevented them from discharging such a duty, stating that ‘the confidential character of patient-psychotherapist communications must yield to the extent that the disclosure is essential to avert danger to others.’<sup>131</sup> The crucial element of the decision in *Tarasoff* was that it created liability in absence of a traditional relationship of proximity between the parties. In this case, there existed neither physical closeness nor an antecedent relationship and, therefore, the action should have failed for not establishing sufficient proximity between claimant and defendant. However, the court held that the identifiable nature of the victim was such that it made the parties ‘neighbours’ and, consequentially, the victim was owed a duty of care.

The decision in *Tarasoff* was influential and has been described by commentators as ‘one of the single most celebrated cases in the recent history of American tort law’.<sup>132</sup> Furthermore, ‘in more than thirty years since this seminal decision, *Tarasoff*-type duties have been widely accepted throughout the [United States] and imposed through either common law or statute’.<sup>133</sup> It has subsequently been extended in a number of judgments, notably in *Durflinger v Artiles*,<sup>134</sup> which held that a psychiatrist could owe a duty to disclose to a finite class of identifiable victims, and *Reisner v The Regents of the*

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<sup>130</sup> *Ibid.*

<sup>131</sup> *Ibid.*

<sup>132</sup> Lake, P., ‘Revisiting *Tarasoff*’ (1994) Albany L Rev 97, p. 97.

<sup>133</sup> *Santana v Rainbow Cleaners Inc* 969 A 2d 653 (Rh. Is. 2009) at 660.

<sup>134</sup> (1984) 727 F 2d 888. The defendant released a patient who had been committed to their institution following the attempted murder of their grandparents. A week after his discharge, the patient murdered both his mother and younger brother. The patient’s propensity for violence towards his own kin meant that his relatives were identifiable victims.

*University of California*, where it was held that a clinician owed a duty to sexual partners of a woman with HIV, despite the class of potential victims being unidentifiable.<sup>135</sup>

However, Knoppers contends that judgments such as *Tarasoff* and *Durflinger* offer little in terms of guidance in respect of the nondisclosure of genetic information, arguing that

‘it is the patient’s actions which are likely to harm others in the case of a threat of violence, in the case of genetic conditions, the patient is not putting relatives at risk by carrying the gene mutation because the relatives already have the mutation or not.’<sup>136</sup>

Yet this is arguably a narrow interpretation of the *Tarasoff*-type duty, which Laurie instead suggests are actually examples of situations where a defendant ‘is privy to important information through the medium of a patient which could be used to protect third parties from harm.’<sup>137</sup> The common position in the patient violence and genetic risk scenario is that the defendant institution (other than the patient themselves) is the only party capable of providing a warning to those who are at risk, and judgments in the American courts appear to support Laurie’s broader interpretation.

A duty to disclose has been upheld in cases involving contagious diseases, with some decisions predating the creation of the *Tarasoff* duty.<sup>138</sup> The duty has also been extended to non-contagious diseases where relatives share the same epidemiological risk. In *Bradshaw v Daniels*<sup>139</sup> a clinician was held to owe a duty to the patient’s wife to warn her of the risks of exposure to the source of her husband’s disease – Rocky Mountain

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<sup>135</sup> (1995) 37 Cal Rptr 2d 5180. See also *Di Marco v Lynch Homes-Chester County Inc* 525 Pa 558, 583 A 2d 422 (Pa. 1990), which concerned transmission of Hepatitis B. In both instances that duty was held to be discharged if the defendant informed the patient, which, in *Di Marco* and *Reisner*, the clinician failed to do. The liability of clinicians towards sexual partners has also been litigated in Australia: see *BT v Oei* [1999] NSWSC 1082 and *PD v Harvey* [2003] NSWSC 487.

<sup>136</sup> Knoppers, B.M., *et al*, ‘Professional Disclosure of Familial Genetic Information’ (1998) 62 AM J Hum Genet 474, p. 481.

<sup>137</sup> Laurie, G.T., ‘Obligations arising from Genetic Information – Negligence and the protection of Familial Interests’ [1999] CFLQ 109.

<sup>138</sup> See *Edwards v Lamb* 45 A 480, 484 (NH 1899), where liability was upheld for failing to warn the patient’s wife of the risk of infection; *Skillings v Allen* 173 NW 663 (Minn. 1919), in which the clinician owed a duty to the parents of a patient with scarlet fever; *Davis v Rodman* 227 SW 612, 614 (Ark. 1921), where a clinician was held liable for the spread of typhoid; *Jones v Stanko* 160 NE 456, 458 (Ohio 1928), in which a clinician was in breach of his duty to disclose regarding black smallpox.

<sup>139</sup> 845 SW 2d 865 (Supreme Court of Tennessee 1993).



spotted fever.<sup>140</sup> Reversing the appellate court's decision, the Supreme Court of Tennessee concluded that it was appropriate 'to impose upon a physician an affirmative duty to warn identifiable third parties in the patient's family against foreseeable risks emanating from the patient's illness.'<sup>141</sup>

A *Tarasoff* duty has also been raised in the context of familial genetic information. In *Pate v Threlkel*<sup>142</sup> the claimant alleged that her mother's doctor was negligent in his failure to disclose that the strain of cancer he had treated her mother for (medullary thyroid carcinoma) was genetically transmissible. The claimant argued that had she been apprised of the hereditary nature of the disease she would have sought genetic testing and, if necessary, early preventative treatment. Nondisclosure of the condition's genetic component had prevented her from doing so. The Supreme Court of California rejected the claimant's submissions, holding that a clinician did not owe a duty to members of a family to disclose genetically transmissible conditions that a patient was undergoing treatment for. It considered that to require clinicians 'to seek out and warn various members of a patient's family would often be difficult or impractical and place a heavy burden upon the physician.'<sup>143</sup> Furthermore, the court held that were such a duty to exist it would be discharged by merely informing the patient that, firstly, their condition is genetically transmissible and, secondly, their blood relations should seek screening and/or treatment. This perspective on the discharge of the duty is consistent with that adopted in *Reisner*, where it was decided that informing the patient of her HIV status would have fulfilled the duty to her sexual partners. Thus the implication in *Pate* was that a duty to disclose would arise when a clinician failed to disclose to the patient that their condition was genetically transmissible, although this permutation of the facts has yet to be litigated.

The applicability of a duty to disclose to genetic conditions was then revisited by the New Jersey Superior Court Appellate Division in *Safer v Estate of Pack*,<sup>144</sup> in which the claimant learned that her father had previously suffered and died from retroperitoneal cancer, a condition that the claimant was undergoing treatment for. As in *Pate*, there was a hereditary risk to the claimant's health and her father's doctor had failed to disclose this

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<sup>140</sup> A tick borne disease caused by the bacterium *Rickettsia Rickettsii* and a potentially fatal human illness in North and South America. It is transmitted by the bites of infected ticks and typical symptoms include fever, headaches, abdominal pain, vomiting and muscle pain.

<sup>141</sup> *Bradshaw*, above, n 139.

<sup>142</sup> 661 So 2d 278 (Supreme Court of Florida 1995).

<sup>143</sup> *Ibid.*, at 282.

<sup>144</sup> 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996).

fact to her, which, it was alleged, amounted to negligence as it deprived the claimant of screening, prompt detection and treatment. Drawing analogies with contagious disease litigation and *Tarasoff* duties, the court concluded that ‘[i]n terms of foreseeability ... there is no essential difference between the types of genetic threat at issue here and the menace of infection, contagion or threat of physical harm.’<sup>145</sup> Furthermore, it considered that ‘[t]he individual or group at risk is easily identified, and substantial future harm is easily identified or minimized by a timely and effective warning.’<sup>146</sup> The judgment in *Safer* therefore imposes a duty on clinicians towards those individuals ‘known to be at risk of avoidable harm from a genetically transmissible condition.’<sup>147</sup> The court was not persuaded by the arguments in *Pate* regarding the burden such a duty would place upon medical professionals, expressly distinguishing the earlier judgment, stating that ‘a duty to warn of avertable risk from genetic causes ... is sufficiently narrow to serve the interests of justice.’<sup>148</sup>

### *UK Jurisprudence*

A *Tarasoff* scenario has yet to be litigated in the UK. One of the closest permutations of facts is at present found in *Palmer v Tees Health Authority*.<sup>149</sup> The claim was brought by a mother whose daughter was abducted and murdered by a former patient of the defendants, who had previously confessed during therapy to having sexual feelings towards children. The patient had been released as an outpatient but had failed to attend his recent hospital appointments. He also resided in the same street as his victim. However, the Court of Appeal found the parties to be insufficiently proximate for a duty of care to exist in respect of mother or daughter, as the victim was perceived to be at no greater risk than any other child, placing her within a potentially indeterminate class of ‘at risk’ individuals. As Stuart-Smith LJ summarised:

‘it is at least necessary for the victim to be identifiable ... to establish proximity ... it seems to me that the most effective way of providing protection would be to give warning to the victim ... so that some protective measure can be made ... and the

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<sup>145</sup> *Ibid.*, at 1192.

<sup>146</sup> *Ibid.*

<sup>147</sup> *Ibid.*

<sup>148</sup> *Ibid.*

<sup>149</sup> [2000] PIQR P1.

most effective precaution cannot be taken because the defendant does not know who to warn. This consideration suggests to me that the Court would be unwise to hold that there is sufficient proximity.<sup>150</sup>

The conclusion in *Palmer* may at first blush appear to preclude the possibility of a *Tarasoff* type duty in English tort law. However, the judgment is consistent with American jurisprudence. In *Thompson v County of Alameda*<sup>151</sup> a juvenile offender with a known propensity for violence towards children was temporarily released into his mother's custody, whereupon he murdered a young boy. The offender had previously intimated to his doctors that he would kill one of the children that lived in his neighbourhood if released, though he never identified a specific victim, merely the geographical proximity. The Supreme Court of California held that a *Tarasoff* duty could not extend to an unidentifiable victim, even if the locality from which they would be drawn was known. The victim did not become identifiable by virtue of residence in a specified location.

The judgment in *Thompson* and Court of Appeal decision in *Palmer* might initially appear to be at odds with the earlier American decision of *Durflinger*, wherein it was held a *Tarasoff* duty could extend to an identifiable class of victims. However, the judgments can be reconciled because *Durflinger* extended the duty to disclose only where the class was finite. The duty arose in that case because the threat was to the perpetrator's family and not the wider public, as was the case in *Thompson* and *Palmer*. The distinction appears to be based upon the practicability of discharging the duty of care: if a patient makes a directed threat against their nephew or niece or the neighbour's child then the clinician's duty can be discharged by warning the identified victim or (in all likelihood) their parents, whereas if a patient broadly threatens to murder a child who resides in the borough of Southwark, the clinician's duty becomes potentially impossible to fulfill. The suggestion is that had the claimant's daughter in *Palmer* been identifiable or one of a finite class of victims, then a duty of care would have arisen.

The supposition that a *Tarasoff* type victim would have succeeded in *Palmer* is leant further weight by the judgments in *Bromley v United Kingdom*<sup>152</sup> and *K v Secretary*

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<sup>150</sup> *Ibid.*, at 12-13.

<sup>151</sup> 614 P 2d 728 (Cal. 1980).

<sup>152</sup> (Unreported) ECHR 23<sup>rd</sup> November 1999. The claimant's daughter was murdered by a man who had failed to return to prison after home leave. It was alleged that the prison service had been negligent in permitting home leave and by failing to capture the prisoner after he had absconded. The domestic court struck out the claim as the claimant's daughter was an ordinary member of the public, chosen at random by her murderer, thus the claimant could not establish either

of *State for the Home Department*,<sup>153</sup> where the necessity of being an identifiable victim is again made apparent. Dismissing a pre-action application for disclosure under the Civil Procedure Rules, Smith J observed in *K*:

‘This claimant cannot claim any special relationship of proximity. She cannot show that the Secretary of State should have been any more aware of her, as a potential victim ... than any other member of the public ... The facts relating to proximity are simple and are not in dispute. Miss K was an ordinary member of the public with no special relationship of proximity to the Secretary of State.’<sup>154</sup>

At first instance, Holland J concurred. He said:

‘Any range of contemplated victims would be remote, extensive and indirect depending upon that third party[’s] ... choice as to whether to obey the law or whether to commit some (and if so, what) crime involving a person or persons whose identity was wholly speculative ... Essentially, the claimant could not be identified as a potential “victim” and consequently was outwith the proximity that is a key element of a duty of care situation.’<sup>155</sup>

In the Court of Appeal, it was implied in the speech of Laws LJ that an identifiable victim would succeed in their action, as in such circumstances a nexus would exist between the parties. He stated:

‘in third agency cases the law *in principle* looks for a ‘special relationship’ between claimant and defendant before it will find a duty of care ... [a] factor in the case to provide a nexus between claimant and defendant ... [Where] the damage which the claimant suffers is directly occasioned by the defendant’s acts or omissions, such a

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foreseeability or proximity. It was held that the court’s decision to strike out the claim on these grounds did not amount to a violation of Art 6 ECHR.

<sup>153</sup> [2001] CP Rep 39. A man detained subject to a deportation order, who had a history of violent sexual offences, was inexplicably released into the community and thereafter raped the claimant at knifepoint at the premises where she was employed as a cleaner. She was subjected to further personal indignities, the least of which was the robbery of personal property. The claimant brought an action against the Secretary of State, alleging that the offender’s release and the failure to discharge his deportation order amounted to negligence and a breach of duty.

<sup>154</sup> *Ibid.*

<sup>155</sup> (Unreported) 3<sup>rd</sup> May 2001 at 9.

nexus will generally be taken to be present ... [otherwise] the nexus will have to be found on the particular facts.’<sup>156</sup>

Ultimately the appeal was dismissed because there was ‘no true nexus shown between claimant and defendant’.<sup>157</sup> Arden LJ likewise implied an alternate outcome where the victim is identifiable, explaining that the ‘need to show proximity (meaning closeness of a relevant kind between the appellant and the respondent) ... cannot be established simply by showing the knowledge on the part of the respondent was of a glaring danger to the public’.<sup>158</sup>

The necessity of an identifiable victim if a duty to disclose is to be established is further underlined by the decision in *W & Others v Essex County Council*,<sup>159</sup> in which the claimants were foster parents engaged by the local authority, and their four biological children. A fifteen-year-old boy whom had been placed in the household by the defendant had sexually abused the children. The parents had previously stated that they would not foster any child suspected of, or known to commit, sexual abuse and the defendant had offered assurances that no such child would be placed with them. However, the defendant failed to disclose that the boy had received a caution for indecent assault and was, at the time, being investigated on suspicion of rape. Hooper J, at first instance, concluded ‘that social worker placing a child with foster parents has a duty of care to provide the foster parents such information as a reasonable social worker would provide’.<sup>160</sup> This conclusion was supported in the Court of Appeal by Judge LJ who agreed that ‘there is a duty to make enquiries and provide information to the foster parents before the placement is made’,<sup>161</sup> but also held that ‘the local authority assumed responsibility for the accuracy of its positive assurances to the parents’.<sup>162</sup> Lord Slynn in the House of Lords proffered the Delphic

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<sup>156</sup> [2002] EWCA Civ. 775 at 26.

<sup>157</sup> *Ibid.*, at 30.

<sup>158</sup> *Ibid.*, at 35. Arden LJ later accepts at 45, leaving the door open for *Tarasoff* type duties, ‘that the common law is very porous and susceptible to development’.

<sup>159</sup> [1997] 2 FLR 535; [1999] Fam 90 (CA); [2001] 2 AC 592 (HL).

<sup>160</sup> [1997] 2 FLR 535.

<sup>161</sup> [1999] Fam 90, at 118.

<sup>162</sup> *Ibid.*, at 123. It is arguably a facet of a duty to disclose, particularly in respect of doctor patient disclosure, that inaccurate or incomplete disclosure amounts to a breach of duty. See *Chester v Afshar* [2005] 1 AC 134; *Birch v University College London Hospital NHS Foundation Trust* [2008] EWHC 2237.

observation that ‘the risk was obvious.’<sup>163</sup> The children were identifiable victims, as the family members were in *Durflinger*. The offender resided with them at the behest of the defendant but knowledge about the risk posed by the boy was not disclosed to the parents and, unlike in *Palmer*, the defendant could have exercised the most effective precaution because they knew precisely who to warn.

An identifiable victim also arose on the facts in *Selwood v Durham County Council*, a case that also bears some similarities to *Tarasoff*.<sup>164</sup> Herein the claimant was employed as a social worker for the local authority, which collaborated closely with two NHS trusts to provide integrated social care and mental health services. The claimant was assigned a case concerning a young girl whose father suffered from mental health problems and had a history of violent behaviour. The father was a patient of the NHS trusts and, during treatment, told his doctors that he wished to harm the social worker involved in his daughter’s case. He then later stated he would ‘kill her on the spot’ if he saw her. Despite the severity of the threat and the patient’s known history of violence, neither the claimant nor her employer was apprised of the situation. When the patient was temporarily discharged from hospital, he attacked the claimant with a knife, inflicting serious injuries. The claimant sued her employer and the NHS trusts in negligence, but it was held at first instance that neither trust owed her a duty of care in respect of the actions of a third party. However, the Court of Appeal allowed the claimant’s appeal and sent the matter to trial, Dame Smith, delivering the judgment of the court, concluding that:

‘this appellant was not one of the world at large; she was one of a small group of social workers, working in close proximity and cooperation with the second and third defendants’ own employees ... the judge erred in failing to consider the special position of this appellant. I have done so and I conclude that it would be open to a trial judge, taking the particular relationship between the parties into account, to conclude that it was fair, just and reasonable to impose a duty of care on the NHS trusts.’<sup>165</sup>

Dame Smith’s reasoning bears similarities to that in *Tarasoff* and, particularly, *Durflinger*, where it was held that a defendant could owe a duty of care to a finite group of identifiable victims. The claimant in *Selwood* argued that she was in a position of quasi employment

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<sup>163</sup> [2001] 2 AC 592 at 598.

<sup>164</sup> [2012] PIQR P20.

<sup>165</sup> *Ibid.*, at 456.

with the NHS as a result of the collaboration between Durham Council and the trusts in respect of social work and mental health and a duty was owed on this basis. However, it may also be argued that because she had been the specific target of the threats, the claimant was an identifiable victim – as had been the case with the patient’s ex-girlfriend in *Tarasoff*. It was therefore fair, just and reasonable to impose a duty of care because the NHS trusts (and only the trusts) were in a position to take the most effective precaution: namely to issue a warning to the claimant and her employers. This contrasts with the situation in *Palmer* where such a precaution could not be taken because the victim was one of a potentially infinite group of persons who were at risk.

It is therefore apparent that a duty to disclose is a possibility within English tort law, as demonstrated by the judgments in *Palmer*, *W* and *Selwood*. Judicial willingness to oversee such an extension has, however, been reserved thus far, a state evidenced in particular by the Court of Appeal’s unwillingness to be drawn on whether or not an identifiable victim would have outright succeeded in *Palmer*, although *Selwood* does indicate that persons in a ‘special position’ can be owed a *Tarasoff*-type duty. By contrast, American tort law has established a duty to disclose, including in respect of genetically transmissible diseases, while maintaining the importance of the doctor-patient relationship and the obligation of confidentiality therein.

It is clear from the cases discussed here that while a body of case law is developing in respect of disclosure to patients, litigation has yet to arise in respect of family members who are not informed of medical risks. Such a duty was articulated in America in *Safer v Estate of Pack* and the paucity of domestic cases mean that this judgment and the case law following *Tarasoff* will be invaluable – if only persuasive – guides as to how to approach the unique challenges posed by the shared genetic heritage of the family unit.

#### **4. Defining ‘Harm’**

##### *Introduction*

Negligence is actionable upon proof of harm; it is fair to say – as Stapleton<sup>1</sup> and Chico<sup>2</sup> do – that harm constitutes the gist of a claim in negligence and ‘completes the cause of action’.<sup>3</sup> Therefore any argument relating to a duty of care must begin with two preliminary questions. Firstly, what kind of harm has the claimant suffered – physical, mental, financial, a setback to other interests? Secondly, does the injury complained of surpass a minimum threshold of harm? Stapleton calls this minimum threshold the ‘gist damage’. Gist damage is the lynchpin of a claim and, while actual recovery is not limited to this core harm, in absence of such there is no action in negligence. A simple illustration of this point is provided by a claim involving a broken leg. In this example, the pain and suffering caused by the break are compensable non-pecuniary losses; however, no actionable claim would exist without the physical injury. The claimant’s broken leg is the ‘gist damage’.

Given that harm is fundamental in proving liability in negligence, it is something of a surprise that – among the conceptual elements of the tort – it ‘is by far the least developed’.<sup>4</sup> On the one hand there is some justification for this position because physical injuries – the mainstay of negligence – are self-evident and it is unnecessary for the courts to provide detailed commentary on the concept of harm in these circumstances. However, when difficulties regarding the definition and categorisation of harm have arisen the issue has not been conceptualised in its own right but repackaged as a question of either duty or causation. To a certain extent it does ‘not matter under which heading the courts address questions of this kind’, but a ‘lack of conceptual clarity may adversely affect the way in which these questions are formulated and dealt with.’<sup>5</sup> Stapleton has argued that a coherent doctrine on the notion of damage is necessary, contending that harm is a word

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<sup>1</sup> Stapleton, J., ‘The gist of negligence’ (1988) 104 LQR 213.

<sup>2</sup> Chico, V., *Genomic Negligence: an interest in autonomy as the basis for novel negligence claims generated by genetic technology* (Routledge-Cavendish, London: 2011).

<sup>3</sup> Nolan, D., ‘New forms of damage in Negligence’ (2007) 70(1) MLR 59-88, 59.

<sup>4</sup> Deakin, S., et al, *Markesinis & Deakin’s Tort Law*, 7<sup>th</sup> ed. (OUP, Oxford: 2007), p. 106.

<sup>5</sup> *Ibid.*, p. 107. Markesinis and Deakin highlight the issue of loss of a chance as an example of this conceptual difficulty. By relying on a balance of probabilities approach in *Hotson v East Berkshire Area Health Authority* [1987] AC 750, the court eschewed the question of whether “‘loss of a chance” fell within the definition of compensatable damage.’



‘bandied about in a number of different contexts, usually without clear definition yet equally without apparent awareness of the importance of precision in its use.’<sup>6</sup> She further argues that precision in the definition of harm is important because ‘[a] fundamental question ... in determining the outer limit of the scope of the tort of negligence is that of what damage is or could be recognised as constituting the minimum for an actionable claim.’<sup>7</sup>

Although it is acknowledged that harm is an underdeveloped concept in the tort of negligence, it is not the aim of this chapter to explore the broader philosophies of damage in negligence, nor propose a coherent set of principles relating to the definition of harm. Instead the focus here is specifically on the issue of minimum actionable damage – ‘gist damage’ – and what injury may constitute this threshold in a claim concerning the nondisclosure of the proband’s genetic risk.

Thus far commentators have attempted to define the gist damage relevant to a broad range of genetic torts. Two notable attempts to present a coherent thesis regarding the injury suffered by claimants are made by Chico and Brownsword. Chico proposes the courts recognise an interest in autonomy and that interference with this interest would constitute the gist of the negligence action. Brownsword advances a broader interest in human dignity as a potential definition of harm in the genetic context. It is with an analysis of these conceptualisations of harm that this chapter begins. One key objection to these formulations of harm that will be explored is their focus on the ability of the individual to be self-determinate and eschewing of the physical burdens of the genetic condition. If compensatory damages are awarded in recognition of this interference with the claimant’s ability to choose, arguably this will not recognise the debilitating effect of the manifestation of a (potentially) avoidable or minimisable condition. The eventuation of the disease is ostensibly more damaging to the individual than the restriction of the ability to exercise a choice.

This chapter will also consider harm formulated as a lack of preparedness and expose the frailties of such a broad approach. Thereafter, the presentation of harm as a loss of a chance to avoid the genetic condition and a loss of a chance to receive medical treatment will be considered. The difficulties the all-or-nothing approach of the balance of probabilities and the courts reluctance to extend loss of a chance arguments to personal injury law will be discussed. Finally the chapter will explore whether or not the eventuation of a genetic condition can itself constitute the gist damage. The main

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<sup>6</sup> Stapleton, above, n 2, p. 213.

<sup>7</sup> *Ibid.*

complaint against this approach is that the defendant does not cause the condition, but it is suggested in the case law that a defendant need not always directly cause harm to be liable in negligence. The approach to genetic conditions adopted in American torts jurisprudence – where failure to disclose a genetic risk has led to liability – will also be considered. It will be argued that conceptualising the gist damage in genetic nondisclosure cases as the eventuation of the condition is the most appropriate way in which to reconcile the issue of undisclosed genetic risks with the concept of harm in negligence.

### *Defining harm as an Interference with Autonomy*

Chico posits that genetic information ‘may be extremely useful in making significant life decisions ... [and] where relevant genetic information about a person exists, but is not disclosed to her, she may feel harmed by this failure.’<sup>8</sup> She argues that were a claimant to bring a claim in negligence at present, it would not be recognised because causing a loss of a chance (i.e. a loss of a chance to avoid the disease or seek medical treatment) is not a recognised harm in personal injury claims unless it surpasses the critical point of balance – in other words, the lost chance must have been, prior to the defendant’s negligence, in excess of 50 per cent. This chapter will return to the concept of lost chances; it is suffice to state at this point that unless the lost chance exceeds 50 per cent, a claim will be rejected because, on a balance of probabilities, the negligence is not the cause of the harm. Thus the claimant will have suffered no gist damage upon which to found a claim.

Chico argues that in absence of judicial recognition of lost chances of avoiding personal injury, an alternate interpretation of harm must be advanced and proposes that ‘[w]hatever the implications of not knowing ... the individual might feel that a failure to inform her of the personal genetic risk is an interference with her autonomy’.<sup>9</sup> The underlying rationale is that in order to be an autonomous individual it is necessary to know relevant information about oneself and a claimant might therefore be injured if their autonomy is curtailed because the proband’s doctor withheld information. This argument is not dissimilar from that employed in litigation concerning patients’ consent (or lack thereof) to medical treatments. Here the claimant’s argument is that ‘[y]ou did not inform me of the risk which has eventuated; but for your failure I would not have consented to the procedure ... [and] sustained injury.’<sup>10</sup> Through recognising a duty in these circumstances,

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<sup>8</sup> Chico, above, n 3, p. 141.

<sup>9</sup> *Ibid.*, p. 146.

<sup>10</sup> Laurie, G.T., Mason, J.K., *Mason & McCall-Smith’s Law and Medical Ethics*, 9<sup>th</sup> ed. (OUP: Oxford, 2013), p. 116.

the courts have acknowledged that ‘respect for a person’s autonomy requires her to be informed of relevant risks before she consents to a medical intervention.’<sup>11</sup> If the failure to disclose genetic risks to the proband’s relatives is interpreted as an interference with autonomy, then the harm suffered is the not knowing relevant information about oneself and if autonomy is viewed from an intrinsic perspective – i.e. that being an autonomous person is in itself valuable – then ‘it is irrelevant whether the genetic disease has, or will, manifest or the extent to which it can be prevented.’<sup>12</sup> Thus once the claimant discovers that genetic risks have been withheld from her ‘she might feel aggrieved on the basis that it amounts to a failure to treat her as a mature and capable adult who able to cope with knowing information about her own genetic risks.’<sup>13</sup>

Although ‘knowing available relevant information is in itself important in being an autonomous person’,<sup>14</sup> an intrinsic perspective of autonomy is difficult to reconcile with the necessity in personal injury claims of a negative outcome befalling the claimant. It is trite that a restriction of an individual’s autonomy is undesirable, but it cannot, as Chico argues, ‘result in harm, irrespective of whether further adverse consequences flow from the failure to respect autonomy’.<sup>15</sup> Such an interpretation of harm would create a tort arguably concerned with the protection of the exercise of an interest and not the recognition and remedying of a harm. Since one of the primary functions of negligence as a tort is to remedy the adverse consequences of the defendant’s careless acts through compensatory damages, if the claimant has not been harmed per se but merely had their possible options reduced then it may be argued that there is no harm (in the traditional sense) worthy of compensation. For ‘harm’, whether physical or mental, to constitute gist damage, a certain threshold must be met. Physical injuries must be a negative physiological change and cannot be benign<sup>16</sup>; psychological harm must constitute a recognised psychiatric disorder.<sup>17</sup> It is therefore difficult to reconcile the intrinsic perspective of autonomy, a curtailing of possibilities, with the necessity for the adverse outcome at the core of negligence.

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<sup>11</sup> Chico, above, n 3, p. 147. On this point, see particularly *Chester v Afshar* [2005], also *Birch v University College London NHS Trust* [2008] EWHC 2237.

<sup>12</sup> *Ibid.*, p. 147.

<sup>13</sup> *Ibid.*

<sup>14</sup> Chico, above, n 3, p. 146.

<sup>15</sup> *Ibid.*, p. 148.

<sup>16</sup> *Grieves v FT Everard* [2007] UKHL 39.

<sup>17</sup> *Alcock v Chief Constable of South Yorkshire Police* [1990] 2 AC 310.

If the restriction of the claimant's autonomy by nondisclosure is accepted as being deleterious in and of itself, the courts could adopt an approach similar to that applied in wrongful pregnancy and wrongful birth litigation and award a conventional sum in recognition of the interference.<sup>18</sup> An infringement of the claimant's autonomy would thus become compensable but, again, in absence of an adverse outcome, the extent of compensation is unlikely to be significant (and could even be paltry), which may militate against attempting to vindicate autonomy through an action in negligence. A distinction between the intrinsic perspective of autonomy and the compensable interference in wrongful pregnancy and wrongful birth litigation is that there remains an adverse outcome in the latter (the pain, suffering and discomfort of pregnancy, if not the birth of a health child).

Rejecting the intrinsic perspective of autonomy as a formulation of harm, an alternative proposition is 'what it [autonomy] might have made possible rather than the value of experiencing autonomy per se.'<sup>19</sup> This interpretation would be 'akin to that which English negligence law recognises with respect to nondisclosure of medical risks.'<sup>20</sup> As outlined above, the issue in doctor-patient disclosure litigation is that had the patient's autonomy been respected and the undisclosed risk (which by this point has eventuated) been disclosed, the patient would not have elected to undergo the given procedure and, consequentially, not suffered the adverse outcome.<sup>21</sup> In the context of undisclosed genetic risks, the interference with autonomy could be characterised as preventing the claimant from availing themselves of screening and/or treatment for the condition identified in the proband's genome. If the interference is considered sufficient to constitute gist damage, then the claimant has a cause of action. Since recovery is not limited to the gist damage but encompasses consequential harm as well, it becomes possible for a claimant to present the manifestation of a treatable genetic conditional as being consequential – and thus compensable – damage. An analogy can be drawn with *Chester v Afshar*,<sup>22</sup> wherein the claimant was not apprised of a statistically low risk of spinal injury inherent in the procedure she was to undergo. When the risk eventuated the claimant sued and the core issue for the courts was whether the defendant had caused her harm. The key point for

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<sup>18</sup> *Rees v Darlington Memorial Hospital NHS Trust* [2003] UKHL 52.

<sup>19</sup> Chico, above, n3, p. 148.

<sup>20</sup> *Ibid.*

<sup>21</sup> Again, see *Chester v Afshar* [2004] UKHL 41.

<sup>22</sup> [2004] UKHL 41.

current purposes is that the risk was inherent in the operation and not caused by the defendant's negligence – genetic conditions could similarly be characterised as inherent in the claimant's genome. In *Chester*, the majority in the House of Lords held a common view that the *Chester*-type action was 'essentially concerned with protecting the patient's right to choose – that is, her autonomy.'<sup>23</sup> However, full compensation, rather than a sum reflecting the frustration of the claimant's self-determination, was awarded. In the context of genetic risks, if the gist damage is constituted as an interference with autonomy and the underlying rationale of the majority in *Chester* applied, it (arguably) becomes irrelevant that the clinician does not cause the disease providing the risk could potentially be avoided through disclosure. Chico, however, argues that in this scenario the loss is the 'inability to be able to choose to avoid the risk ... as opposed to the genetic condition itself. Thus, the damages awarded would reflect the interference with autonomy, as opposed to the direct physical aspects of the genetic condition.'<sup>24</sup> Her point here is that while the value of autonomy may be construed as what it makes possible, what it facilitates might not be the averting of the condition. She argues that '[p]eople can make rational decisions to undergo treatments or undertake avoidance measures even though they know that the chance they will make any difference to the manifestation of the risk is low'.<sup>25</sup> Alternately, a person's autonomy may be interfered with even when there is nothing that can be done – or there is no desire on the part of the individual to seek treatment – where the withheld information is relevant to decisions about one's life.<sup>26</sup>

The problem with casting the net so wide is that it becomes increasingly difficult to argue that an interference with autonomy is harm that is compatible with a claim in negligence. If an individual's autonomy is not respected and the consequences of that infringement are adverse (i.e. that a risk which could have been avoided eventuated) then negligence could facilitate recovery for both gist damage and consequential harm. A similar argument might be advanced where the interference prevented the claimant availing herself of treatment (i.e. chemoprevention) that would have minimised or reduced the risk of the genetic condition manifesting. However, if the interference is couched as preventing the effective exercise of general decisions in respect of one's life (as opposed to medical treatment) then it is debateable that such could form the gist of a negligence claim.

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<sup>23</sup> Laurie, Mason, above, n10, p. 129.

<sup>24</sup> Chico, above, n3, p. 150.

<sup>25</sup> *Ibid.*

<sup>26</sup> *Ibid.*

Accepting a broad conception of autonomy would mean that gist damage in these claims would be difficult to accurately and consistently define. For example, a claimant could validly argue that the nondisclosure of a genetic risk interfered with their autonomy because they did not go on a round the world cruise or elected to have children when knowledge of the risk would have dissuaded them. Both of these scenarios are valid in that the claimant's autonomy has been infringed but the question is which should give rise to a compensable claim. Is the definition of gist damage any interference with autonomy that curtails the claimant's ability to choose? If this is correct, what type of interference (if any) would be considered *de minimus*? A limit is necessary to maintain the practicability of negligence, but the question is where should such limits be drawn. Chico suggests the caveat 'important decisions'<sup>27</sup> but this only raises a further question: important to whom? What is important in the context of an individual's life is a subjective notion, the person who does not go on a round the world cruise and the one who would not have had children are both equally aggrieved, their autonomy equally infringed by the withholding of the proband's genetic risks, thus how can it be convincingly argued that one is deserving of compensation and the other not?

A further problem is that this broad interpretation of harm would require recognition of a new head of damage in tort. Autonomy as a principle has no doubt influenced certain judicial decisions<sup>28</sup> and the judiciary has recognised (and emphasised) the 'growth in autonomy-based arguments over the last 20 years'.<sup>29</sup> Furthermore, the prevalence of autonomy in medical law has also led to commentators considering whether the law is moving towards recognising a tort of infringement of autonomy.<sup>30</sup> However, infringing autonomy does not currently constitute a recognised harm in negligence.<sup>31</sup> Thus it cannot be argued that a defendant has negligently infringed the claimant's autonomy.

Self-determination is, however, a key component in cases concerning doctor-patient risk disclosure.<sup>32</sup> Yet while the underlying rationale may be characterised as one of respecting patient autonomy, the gist of these claims is couched as being that the patient

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<sup>27</sup> *Ibid.*, p. 152.

<sup>28</sup> *Rees v Darlington Memorial Hospital NHS Trust* [2004] 1 AC 309; *Chester v Afshar* [2005] 1 AC 134.

<sup>29</sup> Laurie, Mason, above, n 10, p. 129.

<sup>30</sup> See Mason, J.K., *The Troubled Pregnancy* (Cambridge University Press: Cambridge, 2007).

<sup>31</sup> For a detailed discussion of the conceptual and philosophical basis of autonomy and how these could be shaped into as a new head of damage in tort, see Chico, above, n 3, pp. 37-71.

<sup>32</sup> See chapter two.

would not have consented to undergo the operation had the doctor elected to disclose the risk. Therefore the risk would not have eventuated. The manifesting of physical or mental harm is significant in these cases and an argument based solely on an interference with autonomy (where no adverse outcome occurs) would likely be viewed unfavourably. If an autonomy-based interpretation of harm is to be successfully applied to claims for the nondisclosure of genetic risks then it would need to be couched in similar terms, i.e. that the risk would not have eventuated had the doctor disclosed the relevant information. If autonomy is accepted as forming the gist damage on this basis then, per *Chester*, the eventuating risk would be consequential damage despite not being a direct result of the defendant's negligence. The problem here is that few genetic conditions can actually be avoided per se, thus requiring an opportunity to avoid the risk could restrict the scope of a duty to disclose to a point where it is broadly inapplicable. Therefore instead of avoiding the risk outright, the threshold would need to be that therapies could have minimised or reduced the risk in a more than minimal way.

A final, conceptual criticism of a broad, autonomy-based construction of harm is that it is not representative of the injury sustained by the claimant when information about the proband's genetic risks is withheld. Although the autonomy of blood relations has been infringed because they cannot (arguably) act autonomously in absence of full information, the injury is not truly to their autonomy. While there is a restriction of choice, the actual harm is a corporeal interference with the claimant's health. It is foreseeable that in practice the point at which claimants will become aware that information has not been disclosed is the point that genetic conditions begin to manifest, as occurred in the American case of *Safer v Estate of Pack*.<sup>33</sup> It might be suggested that formulating the harm as an interference with the individual's autonomy is to digress from the practical implication of nondisclosure on the proband's blood relations. In *Safer*, for instance, the complaint was not that the father's doctor had infringed the claimant's autonomy but that his failure to disclose had injured her health. If, as Chico argues, the loss is 'the interference with autonomy ... as opposed to the genetic condition' and the damages awarded do not reflect the physical aspects of the condition, then the consequences of the doctor's negligence become an elephant in the room. An avoidable or reducible risk has eventuated, harming the claimant's health, but the complaint in law is that the individual was denied the opportunity to choose whether to avoid or reduce the risk. To construct harm in a way that does not account for the manifesting of an avertable or reducible risk, either as gist or consequential damage, is antithetical as it undervalues physical health and

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<sup>33</sup> 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996).

wellbeing. Autonomy is important and intimately bound up with medical decision-making but to create a duty based on a concept of harm that values autonomy above physical and mental health is counterintuitive.

*Defining harm as an interference with Human Dignity*

A second interpretation of the harm caused by the nondisclosure of genetic risks is an interference with human dignity. The concept is closely related to the principle of autonomy as ‘the failure to treat an individual as an autonomous person could interfere with her sense of self respect and dignity’<sup>34</sup> and their application as the basis of tortious claims share some similarities. Dignity, however, is arguably a broader concept than autonomy, a multifaceted thing, and herein lies one of the key objection to this formulation of harm, a point to which we will return.

An interest in human dignity is proposed as the basis of claims arising from genetic technologies by Brownsword,<sup>35</sup> who argues that such a general principle ‘offers a real prospect of novel claims at least being brought forward and given serious consideration.’<sup>36</sup> He suggests that ‘the flexibility of such a cause of action gives it some chance of staying connected to rapid technological development.’<sup>37</sup> However, Kuhse is sceptical about the relevance of human dignity, arguing that it has ‘a very dubious role in contemporary bioethical discourse’ and, furthermore, that ‘[i]t is a slippery and inherently speciesist notion, it has a tendency to stifle argument and debate and encourages the drawing of moral boundaries in the wrong places.’<sup>38</sup> Brownsword too recognises that human dignity is ‘an elusive concept, used in many senses by moral and political philosophers.’<sup>39</sup> However, he notes that ‘[i]n modern debates ... it regularly appears in two very different roles, in the one case acting in support of individual autonomy ... in the other case, acting as a constraint on autonomy’.<sup>40</sup> He identifies these two ‘roles’ as human dignity as

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<sup>34</sup> Chico, above, n 3, p. 148.

<sup>35</sup> Brownsword, R., ‘An interest in human dignity as the basis for Genomic Torts’ (2000) 42 *Washburn Law Journal* 413.

<sup>36</sup> *Ibid.*, p. 486.

<sup>37</sup> *Ibid.*

<sup>38</sup> Kuhse, H., ‘Is there a tension between autonomy and dignity?’ in Kemp, P., et al (ed.), *Bioethics and Biolaw Volume II: Four Ethical Principles* (Rhodos International: Copenhagen, 2000), p. 74.

<sup>39</sup> Brownsword, above, n 35, p. 419.

<sup>40</sup> *Ibid.*



empowerment and human dignity as constraint. Brownsword's argument is based upon human dignity as empowerment and thus it is this interpretation that is considered here.<sup>41</sup>

The conception of human dignity as empowerment 'is very closely linked with modern human rights thinking.'<sup>42</sup> Human dignity is one of the foundational ideas of the Universal Declaration of Human Rights (1948), the preamble providing that 'recognition of the inherent dignity and of equal and inalienable rights of all members of the human family'. Art 1 of the Declaration similarly proclaims '[a]ll human beings are born free and equal in dignity and rights.' The Convention on Human Rights and Biomedicine acknowledges dignity, stating in Art 1 that signatories of the convention 'shall protect the dignity and identity of all human beings'. The Human Genetics Commission also incorporated the concept of dignity in the fundamental principles it applied to personal genetic information, stating that '[r]espect for persons affirms the equal value, dignity and moral rights of each individual.'<sup>43</sup> Brownsword advances these fundamental principles and declarations as evidence it is recognised each and every human being has inherent dignity. He further explains it is this inherent dignity that is the foundation of the possession of inalienable human rights. Thus, conceived as empowerment, human dignity is 'much more than a background implication that we can tease out of a number of particular rights ... [but] the infrastructure on which the entire superstructure of human rights is constructed.'<sup>44</sup> Brownsword argues that 'a regime of tort law *self-consciously and explicitly* equipped with such a conception of human dignity' could respond to perceived wrongs generated by genetic technologies.<sup>45</sup> Applying this argument to the context of nondisclosure, it could be argued that the failure to disclose pertinent genetic information amounts to an interference with the dignity of the proband's blood relations, as it prevents them from leading an autonomous life because they lack significant information that may impact upon their free choices.

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<sup>41</sup> For a discussion of human dignity as constraint, see *ibid.*, pp. 420-427.

<sup>42</sup> Brownsword, R., 'Bioethics Today, Bioethics Tomorrow: Stem Cell Research and the "Dignitarian Alliance"' (2003) 17 *Notre Dame Journal of Law, Ethics and Public Policy* 15, p. 21.

<sup>43</sup> Human Genetics Commission, *Inside Information: Balancing Interests in the use of Personal Genetic Information* (London, 2002), paragraph 2.20.

<sup>44</sup> Brownsword, above, n 35, p. 420. For examples of the recurring use of dignity in international human rights legislation, see Clapham, A., *Human Rights in the Private Sphere* (OUP: Oxford, 1996), p. 143.

<sup>45</sup> *Ibid.*, p. 427 (emphasis in original). Brownsword discusses claims based on human dignity in relation to pregnancy and designer babies, control of the outward flow of genetic information by the proband, a right not to know, property in the human body and genetic discrimination.

Whether human dignity is conceived as empowerment or constraint, both interpretations immediately raise the same question: why would it be necessary to recognise an interest in human dignity, when – in the modern context – dignity appears to be synonymous with autonomy. Dignity as empowerment ostensibly permits an individual to lead an autonomous life and make autonomous decisions and a tort based upon this empowerment would vindicate the interest when the ability to act autonomously is negligently infringed. As Laurie writes, privacy, liberty and autonomy ‘prescribe the way in which individuals are to be treated in Western society ... [and] these constructs are all adjuncts to a view of human dignity that is prevalent in our society.’<sup>46</sup> Therefore it may be argued that it is preferable to protect the concepts encapsulated by the label ‘dignity’ on an individual basis as opposed to through recognition of a broad cause of action that will possibly fall prey to a lack of certainty.<sup>47</sup> Brownsword recognises this inherent issue, noting that the ‘obvious problem with such a generalised principle or open-ended cause of action ... is that it leaves too much to interpretation.’<sup>48</sup> Achieving judicial consistency may therefore prove to be a problematic and a piecemeal approach can lead to conceptual and practical difficulties.<sup>49</sup> If the interest protected by a tort is not definable with some degree of certainty, then it becomes difficult for defendants to effectively discharge the corresponding duty.

The approach of the judiciary to extending the duty of care is also notably cautious and a concept as broad as human dignity is likely to be viewed sceptically. The prospect of judicial scepticism is supported by the reservations of the Court of Appeal towards a generalised tort for breach of privacy in *Wainwright v Home Office*, wherein Mummery LJ explained:

‘I foresee serious definitional difficulties and conceptual problems in the judicial development of a “blockbuster” tort vaguely embracing such a potentially wide range of situations ... the creation of a new tort ... could give rise to as many

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<sup>46</sup> Laurie, G.T., *Genetic Privacy: a challenge to medico-legal norms* (Cambridge University Press: Cambridge, 2002), p. 84.

<sup>47</sup> For example, in the UK, equality is protected by Discrimination Law, while the common law and statute protect autonomy (e.g. negligence and the Mental Capacity Act), liberty (e.g. false imprisonment and the Human Rights Act) and privacy (e.g. the Human Rights Act, confidentiality, and the Data Protection Act).

<sup>48</sup> Brownsword, above, n34, p. 486.

<sup>49</sup> The law relating to psychiatric injury is one such example of this difficulty and the courts themselves have acknowledged that the search for principle has been abandoned.

problems as it sought to solve. A more promising and well trod path is that of incremental evolution, both at common law and statute ... of traditional nominate torts pragmatically crafted as to conditions of liability, specific defences and appropriate remedies, and tailored to suit significantly different privacy interests and infringement situations.<sup>50</sup>

Given the prevailing caution to extending the duty of care and judicial aversion to ill-defined concepts, the recognition of harm as an interference with human dignity is (at present, at least) an unlikely development. Brownsword, however, contends that because a dignity-based tort would be ‘very closely related to existing notions of human rights and the importance of individual autonomy ... [it] would not represent major changes of direction for either English or American tort law.’<sup>51</sup> This point is true enough yet the compartmentalised nature of UK law means that the constituted elements of dignity (autonomy, equality etc.) are defined and protected separately.<sup>52</sup>

Defining harm as an interest in human dignity also raises the same conceptual objection as an interest in autonomy, namely that – in the context of nondisclosure of genetic risks – it does not adequately reflect the injury that the claimant will complain of. Like with autonomy, the gist damage is the interference with human dignity (and the underlying ability to exercise free choice) and not the onset of the genetic condition, therefore damages would reflect the infringement of dignity (which in itself would raise an issue of quantum – what is sufficient compensation?) and not the physical burden of the disease. Again, the condition could be characterised as consequential damage, but if the harm is located within a framework of human dignity it is not certain that the physical manifestation of a genetic disease will be seen as consequential and, therefore, compensable. The courts may view an infringement of empowerment-dignity as solely limiting the claimant’s ability to freely choose – the value of which in these circumstances would have been to choose to undergo screening and preventative treatment. Therefore the loss of the ability to choose to seek medical interventions would be compensable harm but the genetic condition eventuating would not be. The risk in this outcome is that it reduces the clinician’s culpability to the restriction of free choice and absolves them of culpability for the ultimate consequence of their negligence – the manifestation of a genetic risk that could have been avoided or minimised through disclosure.

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<sup>50</sup> [2002] QB 1334, at 60.

<sup>51</sup> Brownsword, above, n 261, p. 486.

<sup>52</sup> See above, n47.

### *Defining harm as a lack of Preparedness*

Another way in which the harm caused by nondisclosure of genetic risk may be articulated is as a lack of preparedness. This concept is linked to both autonomy and dignity and essentially the claimant would be arguing that the disclosure had denied them the opportunity to prepare for the onset of their condition. Preparedness could be characterised as the process of allowing the claimant to come to terms with their future, but it might also be presented as an inability to make informed decisions about one's life (for example, to stop delaying that trip up the Amazon River). It is, therefore, a broad and flexible concept, a trait that it shares with the concept of human dignity discussed in the preceding section.

However, there are three principle objections to this interpretation of harm. The first is that the benefits of disclosure in absence of a therapeutic response are debatable. Evidence exists both supporting and refuting the benefits of disclosure engendering preparedness,<sup>53</sup> however, there is an inherent risk that disclosures made with this purpose in mind could have more of a negative impact than a positive one. As Laurie elucidates 'if disclosure is made to avoid ancillary harm such as psychological upset there is less of a guarantee that the harm in question will, de facto, be avoided.'<sup>54</sup> Thus there exists an inherent uncertainty regarding the positive benefits of disclosure for the purposes of preparedness, which raises a question about the appropriateness of a duty premised upon what may fairly be labelled a temperamental concept.

A second objection is that, from a legal perspective, a duty to disclose based on preparedness is undesirable because of the uncertainty it would introduce. Defining sensible (and fair) boundaries would prove difficult and the breadth of potential harms would expose the medical profession to claims arising as a result of claimants' individual (and largely unpredictable) responses and values. Preparedness is, without doubt, a subjective concept, and the values and benefits that each individual attaches to being informed of potentially 'shared' genetic risks will vary considerably from person to person. Thus, one claimant may contend that they have suffered injury as a result of nondisclosure because they were not prepared psychologically for the onset of the condition. However, another may justifiably argue that they have been harmed because, if they had known about their deleterious genetic heritage, their life plans would have been better informed.

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<sup>53</sup> *Ibid.*

<sup>54</sup> Laurie, above, n 266, p. 122.

Consequently, they would have indulged in a round-the-world cruise at an earlier point in time because such pursuits are now prohibited by their condition. In both instances, the claimants have arguably experienced harm. The question is, do justifiable reasons exist to acknowledge a claim in one instance and not the other? At first blush, the claimant who suffers psychological upset may be viewed more favourably than the one who cannot realise their life's ambition. However, the inability to achieve an ambition or goal that would – had a disclosure been made – have been realised is arguably no less of an injury if the harm is the lack of preparedness afforded to the individual.

The third objection to preparedness is that negligence relies upon objective notions of harm and these are difficult to reconcile with a concept that is as subjective as preparedness. Whether or not a person feels sufficiently 'prepared' will be strongly influenced by perceptions and values that will be highly individualised. The anticipated variation in the value of foreknowledge, and the potentially broad interpretation of a lack of preparedness, means that it will be difficult to apply a definite scope to the concept. Any attempt to draw acceptable boundaries will likely be insufficiently representative of the spectrum of claimants' grievances. Even if preparedness was deemed a workable legal concept, it is foreseeable that quantifying damages fairly and consistently would prove extremely difficult, if not virtually impossible.

#### *Defining harm as a loss of a chance*

Another alternative definition of the harm caused by the nondisclosure of genetic risks – and one that has roots in negligence – is as a loss of a chance of avoiding the condition. Thus if 'there is a greater than 50 per cent chance that the claimant could have avoided the particular condition if she had known about the risk, she could argue that the manifestation of the genetic condition itself constitutes harm.'<sup>55</sup> One particular difficulty with this approach, however, is that 'there are currently few genetic conditions which can be avoided',<sup>56</sup> but if, as Laurie argues, the harm cannot be the disease itself since 'the HCP in no way causes the condition from which the relatives might suffer'<sup>57</sup> then it logically follows to phrase the harm as a loss of a chance and not as the manifestation of the disease. The problem facing claimants is that the courts have been extremely reluctant to accept arguments in personal injury based upon a loss of a chance of avoiding physical harm.

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<sup>55</sup> Chico, above, n 254, p. 143.

<sup>56</sup> Chico, above, n 254, p. 143.

<sup>57</sup> Laurie, above, n 253. This is a proposition that this chapter will return to, and challenge.

The leading authority on this point is *Hotson v East Berkshire Health Authority*.<sup>58</sup> The claimant, a young boy, fell from a tree and sustained an injury to his hip, which was subsequently misdiagnosed. The misdiagnosis resulted in treatment being delayed and, by the time a correct diagnosis was reached, the claimant suffered necrosis of the hip joint, leaving him permanently disabled. The injury caused by the fall carried with it a 75 per cent chance of the claimant developing necrosis, however. The negligent diagnosis denied him a 25 per cent chance of recovery. In other words, he had suffered a loss of a one in four chance of avoiding necrosis. The claimant argued that the defendants had caused him loss and he was entitled to damages proportionate to the lost chance of recovery, but the House of Lords rejected his claim. On the balance of probabilities, the fall was responsible for his injury and not the negligence of the doctor – in their Lordships’ opinion the injury was legally (if not medically) inevitable when the claimant fell from the tree. The decision is peculiar in one respect in that it disregarded the significance of the claimant’s chances of recovery. These were one in four and, in alternate contexts such as gambling, would be viewed as favourable. There is an obvious disconnect in the law here: on the one hand, doctors are expected to disclose risks that are statistically slight (ten per cent risk of a stroke was highlighted by Lord Bridge in *Sidaway*, a one to three per cent risk was the root of the claim in *Chester*), but on the other clinicians are not regarded as being liable for reducing a patient’s prospects of recovery merely because these did not pass the point of balance and thus are not legally certain. The obvious criticism here is that there are few certainties in medical treatment and any attempt by the courts to impose such is disingenuous.

Despite criticism from Lords Nicholls and Hope, the House of Lords affirmed *Hotson* as the leading authority on loss of a chance in *Gregg v Scott*.<sup>59</sup> Here doctors had negligently failed to diagnose a cancer patient reducing his prospects of recovery from 42 per cent to 25. The claimant argued that their negligence had caused him to lose the chance of a cure (which in terms of cancer is characterised as survival for ten years) but the majority rejected the claim because it did not satisfy the balance of probabilities. Baroness Hale, in particular, argued that it would be problematic to permit loss of chance arguments because ‘almost any claim for loss of an outcome could be reformulated as a claim for a loss of a chance of that outcome.’<sup>60</sup> This, it seems, is the principle objection to arguments premised upon a loss of a chance, since it might enable claims to succeed in part where

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<sup>58</sup> [1987] 2 All ER 909

<sup>59</sup> [2005] AC 176.

<sup>60</sup> *Ibid.*, at 233.

they would otherwise fail. A claimant could thus ‘recover 100 per cent if he proved on a balance of probabilities the loss of the outcome ... [but] would still recover something if he lost that argument but proved he had nonetheless lost some chance of a better outcome.’<sup>61</sup> It could effectively lead to a ‘heads you lose everything, tails I win something situation.’<sup>62</sup>

Lords Hope and Nicholls in the minority thought that the claimant had lost something of value and the law ought to recognise the wrong inflicted. Lord Nicholls argued forcefully that to deny recovery ‘would be irrational and indefensible.’<sup>63</sup> He explained:

‘The loss of a 45% prospect of recovery is just as much a real loss for a patient as the loss of a 55% prospect of recovery. In both cases the doctor was in breach of his duty to his patient. In both cases the patient was worse off. He lost something of importance and value. But, it is said, in one case the patient has a remedy, in the other he does not. This would make no sort of sense. It would mean that in the 45% case the doctor's duty would be hollow. The duty would be empty of content.’<sup>64</sup>

His Lordship makes a compelling point that differentiating between chances above and below the point of balance could render the doctor's duty of care empty of content in particular circumstances. This is because where the claimant's initial chance was less than 50 per cent the law does not regard the deleterious outcome as a consequence of the doctor's negligent actions.<sup>65</sup> He further added that while ‘losing a chance of saving a leg is not the same as losing a leg ... that is not a reason for declining to value the chance for whose loss the doctor was directly responsible.’<sup>66</sup>

It should be noted that the outcome of *Hotson* and *Gregg* are at odds with the approach to loss of a chance in economic loss, where a lost opportunity to litigate a claim,

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<sup>61</sup> Maskrey, S., Edis, W., ‘*Chester v Afshar* and *Gregg v Scott*: mixed messages for lawyers’ (2005) 3 JPI Law 205, p. 213.

<sup>62</sup> *Ibid.*

<sup>63</sup> *Gregg*, above, n 59, at 177.

<sup>64</sup> *Ibid.*, at 180.

<sup>65</sup> This is not to say that the doctor would escape censure, as regulatory bodies such as the General Medical Council or Nursing and Midwifery Council are likely to investigate clinical ‘incidents’, but it would leave the claimant without compensation for the loss they have endured.

<sup>66</sup> *Ibid.*, at 185.

gain employment and negotiate a more profitable business deal are recoverable. Chico therefore suggests that the difficulty ‘is not with loss of chance per se, rather something to do with extending this head of damage to personal injury’,<sup>67</sup> an opinion supported by Baroness Hale’s reticence in *Gregg*. Weir has also argued that while ‘[l]osing a chance of a gain is a loss like the loss of the gain itself, alike in quality just less in quantity: losing a chance of not losing a leg is not the same thing as losing a leg.’<sup>68</sup> Yet Weir’s assessment does not countenance the value of the chance of saving, in his example, the claimant’s leg. If the issue is considered from the claimant’s perspective then it can be argued that the opportunity to save their limb, even if this opportunity is less than 51 per cent, is valuable and therefore loss of such should be compensable.

In the alternative, the loss of a chance (and therefore the gist damage) where the proband’s genetic risks are not disclosed could be articulated as a loss of a chance to acquire medical treatment, as opposed to a loss of chance of avoiding the condition outright. If an underlying purpose of a duty to disclose is to protect of the health of those who may share a patient’s genetic risks, then the harm complained of might be characterised as the denial of medical treatment and the consequential benefits (i.e. treatment) that nondisclosure represents. The following provides an illustration: a patient undergoes genetic screening and is identified as possessing a mutation on the BRCA1 or BRCA2 gene, which increases the chances of them developing breast cancer by between 50 and 80 per cent. Knowledge of the risk means that an individual can opt to undergo preventative therapies, such as a mastectomy or chemoprevention.<sup>69</sup> If the clinician does not disclose this information to the proband’s relatives, and they go on to develop breast cancer, the nondisclosure has denied those individuals the opportunity to seek appropriate medical interventions. It might be argued that this loss of a chance harms the claimant because it prevents mitigation of genetic risk, the eventuation of which could be seen as consequential to the gist damage because the lost chance may have reduced the probability of the condition manifesting. In one sense, this interpretation of harm is simply word play, a shifting of the onus from avoiding the genetic disease to having access to treatments that might have made avoiding the disease possible. Yet if the harm cannot be the disease itself because ‘the HCP in no way causes the condition’<sup>70</sup> then it may be preferable to avoid

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<sup>67</sup> Chico, above, n 253, p. 146.

<sup>68</sup> Weir, T., *Tort Law* (OUP: Oxford, 2002), p. 76.

<sup>69</sup> Preventative drug therapies that reduce the risk of the patient developing cancer in their lifetime.

<sup>70</sup> Laurie, above, n 253. This is a proposition that this chapter will return to, and challenge.



characterising the loss of a chance as a chance of avoiding the disease. If a nondisclosure denies a claimant access to preventative treatment then the doctor's actions – while not solely responsible for the onset of the condition – contribute to its eventuation. The same logic could be applied to the facts in *W & Others*<sup>71</sup> because, though the council did not cause the sexual abuse, they denied the claimants the chance of mitigating the risk by failing to disclose the chequered past of the perpetrator (the foster child) to the claimants' parents. Articulating the harm as a lost chance of acquiring medical treatment also limits the scope of the duty in an arguably sensible way: a disclosure would not be expected in absence of treatment because the benefits of disclosing genetic risks in such circumstances are debatable.<sup>72</sup>

Interpreting the loss of a chance as a lost chance of medical intervention is premised on an assumption that prevention (or risk reduction) is preferable to lengthy, invasive therapies, or, alternatively, that early intervention is beneficial to claimants who are at risk – a fact starkly demonstrated by poor survival rates for sufferers of pancreatic cancer in the UK, who are often diagnosed too late and the cancer is inoperable. The starting point if this interpretation of harm is acceptable would not be whether the claimant's prospects of recovery were beyond the point of balance but whether or not treatment would have been available had the genetic risk been disclosed. The initial enquiry is thus restricted to a 'yes' or 'no' answer. However, thereafter the case law on loss of a chance suggests that the statistical significance of the treatment would be a relevant consideration for the court. Therefore if the treatment has only a 25 per cent chance of averting the onset of a condition then the chance is below the point of balance it would fail a typical analysis of the issue. Relying on percentage chances to impose legal (as opposed to factual) certainty would ignore that 'there is something valuable in having the opportunity to try all you can to prevent a genetic disease'<sup>73</sup> but it is not anticipated that the courts would move away from the all-or-nothing approach of the balance of probabilities. Thus although categorising the harm as a loss of a chance of medical treatment may appear initially sensible, the knotty issue of probability and the necessity of

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<sup>71</sup> [2001] 2 AC 592 (HL).

<sup>72</sup> Almqvist, E., *et al*, 'A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalisation after predictive testing for Huntington's disease' (1999) 64 *American Journal of Human Genetics* 1293; Almqvist, E., *et al*, 'Risk of Reversal in Predictive Testing for Huntington's Disease' (1997) 61 *American Journal of Human Genetics* 945; Wexler, N., 'Genetic Jeopardy and the New Clairvoyance' (1985) 6 *Progress in Medical Genetics* 227.

<sup>73</sup> Chico, above, n 3, p. 150.

legal certainty mean that it is unlikely to avoid the core problem with losses of chance: the need to surpass the point of balance.

Whether there is a sustainable basis for continuing to differentiate between negligence causing an individual to lose a 51 per cent chance and negligence denying a (still statistically significant) 49 per cent chance of recovery remains a moot point and one the Court of Appeal has stated should be left to the Supreme Court.<sup>74</sup> In principle, denying a chance of recovery, treatment or avoiding a risk outright should be compensable harm because a possibility of recovery (such as the 25 per cent chance in *Hotson*) is of value to the claimant. However, Baroness Hale's practical concerns about permitting claims for loss of a chance are not insignificant. As a result, claims concerning nondisclosure of genetic risks, where the chance of avoiding, treating or recovering from the condition are lower than 50 per cent, are unlikely to succeed.

### *Defining harm as the Genetic Condition*

It has been argued that the harm complained of when genetic risks are not disclosed to a patient's relatives cannot be the genetic condition itself. This is because 'the HCP in no way causes the condition from which the relatives might suffer'.<sup>75</sup> The question is whether this argument is sustainable or whether genetic conditions can amount to actionable harm for the purposes of a negligence claim.

The principle objection to a genetic condition forming the gist of a claim appears to be that the defendant's negligence does not cause the deleterious outcome. In other words, the non-disclosure does not cause the condition, it is a product of the claimant's genes and thus outside the defendant's control. At first blush this is an appealing and, ostensibly, well grounded argument. But this objection fails to address the fact that liability in negligence does not always appear to depend upon the defendant's conduct being the direct source of the harm suffered by the claimant. Two cases that illustrate this point are *Chester v Afshar* and *Birch v University College London Hospital NHS Trust*.<sup>76</sup>

In *Chester*, the defendants failed to disclose a (statistically slight) risk of spinal injury, exposing the claimant to a risk of injury that, had the risk been disclosed, might have been avoided due to the claimant seeking a second opinion and delaying the procedure. On this point the claimant argued that 'had she delayed her operation until a later time then, even if she would eventually have had it, the odds she would have faced

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<sup>74</sup> See *Wright (a child) v Cambridge Medical Group* [2011] EWCA Civ 699.

<sup>75</sup> Laurie, above, n 253. This is a proposition that this chapter will return to, and challenge.

<sup>76</sup> [2008] EWHC 2237.

would have been 1-2 per cent.’<sup>77</sup> Lord Hoffmann thought this argument illogical, since the claimant could not definitively prove she would not have had the operation.<sup>78</sup> But as Stapleton explains ‘the fact that, against the a priori probabilities, Miss Chester happened to “win” the syndrome when she had the operation ... does not affect the odds that attach to the hypothetical later operation which, but for the breach, she might have undergone after a delay.’<sup>79</sup> In plain terms the probability of avoiding the risk was between 98-99 per cent, thus had she been apprised of the risk, even if later she had undergone the procedure, it was statistically likely she would have avoided harm.

A critical point for current purposes was that the risk was inherent in the proposed surgery and not dependant on the defendant’s negligence. When the risk eventuated, the claimant successfully sued and recovered for the physical injuries she had sustained. Despite awarding damages for the claimant’s spinal injury, the House of Lords characterised the harm suffered as being a loss of autonomy, thus suggesting the gist of the claim was the principle of patient autonomy, which had been interfered with through a failure to disclose the risk. There is some merit to this for, as Lord Bingham noted, the rationale behind a duty to disclose is ‘to enable adult patients of sound mind to make for themselves decisions intimately affecting their own lives and bodies’.<sup>80</sup>

However, it has been suggested that the majority were attempting to make the decision in *Chester* ‘more palatable’<sup>81</sup> by defining the harm in terms of autonomy. A pertinent question is whether the claimant would have had an actionable claim in absence of physical injury. One might argue that the gist of the claim is the breach of autonomy but it is difficult to sustain this line of argument if an interference with the claimant’s self-determination does not constitute a freestanding claim. If the interference is only actionable once an adverse outcome occurs then the adverse outcome, not the interference with autonomy, is the gist of the claim.

In the context of genetics, genetic diseases may therefore constitute harm even though nondisclosure does not directly inflict the injury. In *Chester*, the negligence was not the root source of the adverse outcome but, as Stapleton notes, ‘breaches of the obligation to warn patients will tend to increase the incidence of the medical risk

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<sup>77</sup> Stapleton, J., ‘Occam’s Razor reveals an orthodox approach to *Chester v Afshar*’ (2006) 122 LQR 426, p. 429.

<sup>78</sup> *Chester*, above, n 22, at 31-32.

<sup>79</sup> Stapleton, above, n 77, pp. 429-430.

<sup>80</sup> *Chester*, above, n 22, at 5.

<sup>81</sup> Street on Torts, p. 158.

occurring', because a greater number of individuals are likely to run the undisclosed risk and, thus, a higher percentage will come to harm.<sup>82</sup> The outcomes – spinal injury or genetic disease – are non-coincidental. If treatment is available for a genetic condition then nondisclosure increases the incidence of the disease through denying access to those preventative therapies. As with the spinal injury in *Chester*, a genetic disease can therefore be characterised as an adverse outcome 'about which a warning was required by the content of the duty'.<sup>83</sup> This, in turn, means 'there is room for the obligation to warn to be seen as grounded in the deterrence of outcomes injurious to *physical integrity*, which of course has long been an interest uncontroversially protected by the tort of negligence.'<sup>84</sup> In the context of genetics, outcomes injurious to physical integrity would constitute the eventuation of risks that could otherwise have been avoided or minimised. Thus genetic diseases may constitute harm despite the fact that the negligence does not inflict them.

A useful analogy can be lifted from the case of *SAAMCO*, where Lord Hoffmann discussed the example of a mountaineer recuperating from an injury to his leg.<sup>85</sup> Applied to the present context, imagine the attending physician negligently fails to disclose a weakness in the mountaineer's leg and he is injured whilst climbing a mountain because his leg collapses. If the treatment he has received is presumed not to be negligent, the doctor has in no way caused the weakness in the leg, but the injury sustained as a result of that undisclosed weakness forms the crux of an action in negligence. It is the eventuating of a risk that could have been avoided or minimised by disclosure that constituted the gist damage. If the weakness is substituted for a treatable genetic risk – say, breast cancer – arguably the same conclusion can be made out: the doctor does not create the deleterious genetic trait, but nondisclosure allows the risk to eventuate.<sup>86</sup>

Further support can be drawn from the case of *Birch*, where the defendants failed to disclose (i) the risk of a stroke inherent in undergoing a catheter angiogram and (ii) that an MRI represented a low risk alternative. The patient underwent the angiogram and suffered a stroke. Thereafter she successfully sued.

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<sup>82</sup> Stapleton, above, n 77, pp. 442-443.

<sup>83</sup> *Ibid.*, p. 446.

<sup>84</sup> *Ibid.*, p. 443 (emphasis in original).

<sup>85</sup> *South Australia Asset Management Corp v York Montague* [1997] AC 191, at 213.

<sup>86</sup> A noteworthy point is that in the example of the mountaineer there is a doctor-patient relationship, but this is a matter of proximity and not harm. Proximity between blood relations and the proband's doctor is discussed in chapter five.

In *Birch* – as in *Chester* – the claimant’s action hinged on the presence of an adverse outcome. Had she not suffered a stroke no claim in negligence would have arisen because the doctor’s negligence would not have caused harm. Thus the gist of the action was the eventuating risk and not the interference with the claimant’s autonomy. The judiciary is demonstrating an increasing respect for autonomy in the medical context but it is unlikely that compensable harm would have existed in either *Chester* or *Birch* had the respective procedures been completed without adverse consequences. Although the claimants could argue (from a moral if not legal perspective) that their self-determination had been restricted, there would have been no ‘loss’ in the accepted sense; the claimants would not have been adversely affected by the nondisclosure of the risk.

Thus the gist damage was the stroke, an adverse outcome that eventuated because of the nondisclosure, but, crucially, the risk was not created by the defendant’s failure to warn but inherent in the proposed procedure. For this reason it can be said that the doctors in no way caused the stroke, just as it can be said that they do not cause genetic disease. However, the nondisclosure in *Birch* meant the claimant could not avoid or minimise the risk of a stroke. In this sense, the nondisclosure ‘causes’ harm because ‘breaches of the obligation to warn patients will tend to increase the incidence of the medical risk occurring’.<sup>87</sup> Therefore the doctor’s negligence need not be the source of the injury in order for it to constitute the gist of an action in negligence. The source of the injury in *Birch* was the angiogram, in *Chester* it was the operation, but in both cases the defendants were liable for the eventuation of the undisclosed risk. Thus whilst the source of a genetic condition may be characterised as the individual’s genes, the eventuation of an undisclosed genetic risk – providing treatment existed for the said condition – is potentially gist damage.

Support for this line of reasoning can also be drawn from cases concerning physical injuries inflicted upon the claimant by a third party. In these types of circumstance, it is axiomatic the defendants are not directly the source of the harm. But liability accrues because the actions of the third party constitute an eventuation of an undisclosed risk, which could have been avoided or minimised by disclosure. The eventuation – the physical injury – is the gist damage.

In the landmark American case *Tarasoff v Regents of the University of California*,<sup>88</sup> the defendants failed to warn the claimant’s daughter about the risk posed to her by an ex-boyfriend. The ex-boyfriend had for a time been a psychiatric patient in the defendants

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<sup>87</sup> Stapleton, above, n 77, pp. 442-443.

<sup>88</sup> 17 Cal. 3d 425 (Cal. 1976).

care and, during therapy, he had confessed to his psychiatrist that he intended to kill the victim once discharged. Despite the obvious severity of this threat, the defendants exercised few precautions and, significantly, made no attempt to apprise the claimant's daughter of the risk. The claimant alleged that the defendants had been negligent in failing to warn her daughter about the risk her ex-boyfriend posed.<sup>89</sup> The Supreme Court of California found in her favour.

The harm in *Tarasoff* can be formulated in the same manner as that in *Birch* and *Chester*. It was the eventuation of the undisclosed risk, which in this case was the victim's murder. It is trite that the ex-boyfriend was the killer – and in this sense the literal 'source' of death – but disclosure could have facilitated the victim avoiding or minimising the risk to her person. The defendants' failure to disclose meant she was unaware of the danger and, in this sense, an analogy can be drawn with an individual who is unaware they are at risk of a genetic condition. In both instances the source of the harm is not the defendants' negligence but their inaction plays a not insignificant part in the risk eventuating, because harm could have been 'easily identified or minimized by a timely and effective warning.'<sup>90</sup>

The failure to warn of the risk posed by a third party was again at issue in *Selwood v Durham County Council*.<sup>91</sup> The claimant was a social worker employed by a local authority involved in close collaboration with two NHS trusts to provide integrated social care and mental health services. The claimant's was assigned to a case involving a young girl whose father suffered from mental health problems and had a history of violent behaviour. The father was a patient of the NHS trusts and, during treatment, told his doctors that he wished to harm the social worker involved in his daughter's case. He later stated he would 'kill her on the spot' if he saw her. Despite the severity of these threats and the patient's known history of violence, neither the claimant nor her employers were warned of the risk. When the patient was temporarily discharged from hospital, he attacked the claimant with a knife, inflicting serious injuries.

It is axiomatic that the defendants in *Tarasoff* and *Selwood* were not the source of the claimants' injuries, but those injuries were the gist of the negligence actions. As in *Chester* and *Birch*, the nondisclosure of risk meant the claimants could not avoid or

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<sup>89</sup> For example, *ibid.* at 433 per Tobriner J: 'Poddar [the ex-boyfriend] persuaded Tatiana's brother to share an apartment with him near Tatiana's residence; shortly after her return from Brazil, Poddar went to her residence and killed her.' Had the defendants disclosed the risk posed by the ex-boyfriend it is foreseeable that these accommodation arrangements would not have been made.

<sup>90</sup> *Safer v Estate of Pack* 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996), at 1192.

<sup>91</sup> [2012] PIQR P20.

minimise the harm. Though the nondisclosures of physical and medical risks are distinguishable in some ways,<sup>92</sup> the gist damage is consistently the adverse outcome – the eventuating of an undisclosed risk. While the defendants are not the source of the deleterious consequences the claimants experience,<sup>93</sup> it is the adverse outcomes, not the nondisclosure, which discloses an action in negligence.

It has been noted that, in the context of genetics, it is thought that a genetic condition cannot constitute harm because ‘the HCP in no way causes the condition’.<sup>94</sup> However, it is apparent that a doctor does not need to be the source of a condition in order to be liable in negligence. Instead, a doctor may be culpable for the physical burden of a disease where an undisclosed risk of said disease (which, with disclosure, may have been avoided or minimised) eventuates. The New Jersey Superior Court Appellate Division appeared to endorse this proposition in *Safer v Estate of Pack*.<sup>95</sup> Here the claimant discovered that her father had previously suffered and died from retroperitoneal cancer, a condition that she was also undergoing treatment for. The condition was hereditary and it was contended that this was known at the time the defendant had treated the claimant’s father. It was alleged that the doctor ‘was required, by medical standards then prevailing, to warn those at risk so that they might have the benefits of early examination, monitoring, detection and treatment, that would provide opportunity to avoid the most baneful consequences of the condition.’<sup>96</sup> In finding for the claimant, the court concluded that circumstances involving genetic conditions were analogous to litigation concerning contagious disease<sup>97</sup> and *Tarasoff*, stating:

‘We see no impediment, legal or otherwise, to recognizing a physician's duty to warn those known to be at risk of avoidable harm from a genetically transmissible condition. In terms of foreseeability especially, there is no essential difference

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<sup>92</sup> Disclosure in *Chester* and *Birch* would have assisted the defendants in securing valid consent, whereas disclosure in *Tarasoff* and *Selwood* would have facilitated the personal safety of the victim.

<sup>93</sup> The source can be characterised as either the third party (*Tarasoff* and *Selwood*) or the non-negligent operation (*Chester* and *Birch*).

<sup>94</sup> Laurie, above, n 253.

<sup>95</sup> 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996).

<sup>96</sup> *Ibid.*, per Kestin JAD at 623.

<sup>97</sup> E.g. *Bradshaw v Daniels* 845 SW 2d 865 (Supreme Court of Tennessee 1993).

between the type of genetic threat at issue here and the menace of infection, contagion or a threat of physical harm.’<sup>98</sup>

The New Jersey Superior Court did not engage in a philosophical assessment of the concept of harm – which, perhaps, reiterates Nolan’s point that harm is generally subsumed into either questions of duty or causation – but equating genetic risks with risks of infection, contagion and physical harm is clearly indicative of the court considering the eventuation of the risk to be the gist of the action. The court’s reference to ‘substantial future harm’<sup>99</sup> is also telling and reinforces the point. Because the complaint is couched in terms of avoiding ‘the most baneful consequences of the condition’,<sup>100</sup> the substantial future harm that the court refers to can only be the physical manifestation of the genetic condition itself. Genetic diseases are therefore capable of constituting gist damage despite the fact that the tortfeasor is not the source of the condition. It is the fact that nondisclosure prohibits individuals from taking steps to minimise a risk that shifts responsibility for an adverse outcome to the defendant.

The decision in *Bradshaw v Daniels*<sup>101</sup> lends further credence to this interpretation of harm. Here a clinician was held to owe a duty to the patient’s wife to warn her of the risks of exposure to the source of her husband’s disease – Rocky Mountain spotted fever.<sup>102</sup> The husband’s disease was non-contagious but the doctor negligently failed to disclose his wife was at the same epidemiological risk and she later died from the condition. In common with genetic diseases, the doctor in *Bradshaw* could in no way be said to be the source of the condition, but he was ‘in a position to know of a risk that may not be obvious to others’.<sup>103</sup> The gist of the action was again the adverse outcome that could have been avoided had a timely warning been given. Reversing the appellate court’s decision, the Supreme Court of Tennessee concluded that it was appropriate ‘to impose

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<sup>98</sup> *Safer*, above, n 82, at 626.

<sup>99</sup> *Ibid.*

<sup>100</sup> *Ibid.* at 623.

<sup>101</sup> 854 SW 2d 865 (Tenn. 1993).

<sup>102</sup> A tick borne disease caused by the bacterium *Rickettsia Rickettsii* and a potentially fatal human illness in North and South America. It is transmitted by the bites of infected ticks and typical symptoms include fever, headaches, abdominal pain, vomiting and muscle pain.

<sup>103</sup> Parker, C., ‘Camping trips and family trees: must Tennessee physicians warn their patient’s relatives of genetic risks?’ (1998) 65 *Tennessee L Rev* 585, p. 597.



upon a physician an affirmative duty to warn identifiable third parties in the patient's family against foreseeable risks emanating from the patient's illness.'<sup>104</sup>

The decisions in *Safer* clearly indicates that the American judiciary has accepted genetic diseases can constitute the gist of an action in negligence. This outcome can be reconciled with a paradigm of liability wherein the defendant is not the source of the harm but, through a failure to warn against a risk, becomes responsible for an adverse outcome. In the cases cited above, the literal source of the harm complained of was either a third party (*Tarasoff* and *Selwood*), a non-negligent operation (*Chester* and *Birch*), a non-negligent exposure (*Bradshaw*) or a deleterious genetic trait (*Safer*). The defendants in these examples can in no way be said to inflict the harm, but their failure to disclose known risks meant that harm could not be avoided or minimised. Thus responsibility for the adverse outcomes that eventuated shifted to the defendants. The gist of an action in negligence can therefore be an adverse outcome that the defendant failed to warn against. This rationale means that genetic diseases can form the gist of an action in negligence, because nondisclosure prevents claimants from minimising or avoiding an adverse outcome, which, in this case, is the eventuating of a genetic disease. The court in *Safer* found 'no essential difference between ... genetic threat ... and the menace of infection, contagion or a threat of physical harm',<sup>105</sup> as it is common to these examples that harm can be 'easily identified or minimized by a timely and effective warning.'<sup>106</sup> It is therefore argued that the eventuating of genetic risks can be the gist of a negligence action and that such is not a radical departure from the formulation of harm all ready present in cases of undisclosed physical and medical risks.

A notable criticism of defining harm as the undisclosed risk of the genetic condition developing into the genetic condition itself is that it considerably limits the scope of the duty of care. It might be suggested that an action based on autonomy would allow recovery in wider circumstances, which, in turn, may have the indirect effect of promoting more widespread disclosure of genetic risks from within the healthcare profession. In contrast, having to 'wait' for the genetic risk to develop into the condition before there is a valid claim would serve to limit the actual number of cases that could be brought. Since

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<sup>104</sup> *Bradshaw*, above, n 101.

<sup>105</sup> *Safer*, above, n 82, at 626.

<sup>106</sup> *Safer v Estate of Pack* 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996), at 1192.

not every genetic risk materialises, the proband's blood relations could only litigate in very narrow circumstances.

It is acknowledged that the proposed definition of harm is more limited in scope than some of the other possible interpretations discussed here. An autonomy-based harm, for example, would permit recovery in a wider range of circumstances because 'harm' is not dependant on the genetic condition eventuating. But autonomy-based claims would require recognition of a new head of damage.<sup>107</sup> Defining harm as the eventuation of a genetic disease grounds a duty to disclose 'in the deterrence of outcomes injurious to *physical integrity*, which of course has long been an interest uncontroversially protected by the tort of negligence.'<sup>108</sup> Thus creating a duty to blood relations can (potentially) be characterised as an extension of the protections for an interest that is all ready legally recognised.

A further hurdle the proposed definition overcomes is that something with no perceptible effect on health or capability is generally not actionable damage. For this reason, the courts are likely to be sceptical about formulating harm as the failure to disclose a genetic risk indicating future ill health. An adverse outcome is, thus far, a necessary ingredient of negligence, a point emphasised by *Grieves v FT Everard & Sons*.<sup>109</sup> The claimants had been exposed to asbestos during the course of their employment and had subsequently developed plural plaques. However, the plaques did not affect the claimants' health, only indicated a potential of future disease. The House of Lords explained that damage is an abstract notion of being worse off – physically, mentally or economically – so that compensation is appropriate and, since the plaques were benign, they were not actionable damage. Thus not knowing of a risk of future ill health is, on this basis, insufficient to constitute harm. The necessity of an adverse outcome is therefore consistent with current rules of tort.

It is therefore proposed that the eventuating of a genetic condition can be 'harm' for the purposes of an action in negligence.

### Conclusion

This chapter has examined several possible interpretations of the harm caused by nondisclosure of genetic risks. It has examined the relative strengths and frailties of harm

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<sup>107</sup> For discussion of autonomy as harm see 'Defining Harm as an Interference with Autonomy' above and Chico, above, n 4, pp. 37-71.

<sup>108</sup> Stapleton, above, n 77, p. 443 (emphasis in original).

<sup>109</sup> [2007] UKHL 39.

defined as an interference with autonomy or human dignity, a lack of preparedness and a loss of a chance. It has been argued – contrary to established lines of thinking – as possible for the genetic condition itself to constitute the gist of the claim. Support has been drawn from both domestic and American case law involving undisclosed risks of harm and it is argued that a defendant need not be the source of a harm for liability to accrue in negligence. This approach is particularly apt because it appears to be recognised in the American decision of *Safer v Estate of Pack*, which involved nondisclosure of a genetic risk. In reaching a conclusion favouring the claimant, the court drew analogies between genetic risks, risks of physical violence and contagious diseases. This interpretation of harm is argued as grounding a duty to disclose to blood relations in physical integrity, an interest that is a mainstay of negligence as a tort. Thus formulating the harm as an eventuation of risk can be reconciled with established interests in tort.

## **5. PROXIMITY, POLICY AND THE DUTY TO DISCLOSE**

### *A Duty to Disclose*

Descendants of a common gene pool will, inevitably, share a percentage of genetic traits. Thus genetically screening a patient will simultaneously reveal information about their genetic heritage and that of their blood relations, since deleterious traits in the proband's genome may also be present in their relatives' DNA. Consequentially the proband's doctor will possess information relevant to both the health of their patient and persons beyond the therapeutic relationship. This raises the question: should genetic information be disclosed to family members? It is suggested here the answer is 'yes' where treatments are available for the relevant condition, especially when expedient diagnosis is crucial to successful therapeutic intervention.<sup>1</sup> The next question is how should the law respond? In absence of legislation, novel claims are invariably articulated through the law of torts and, as explained in previous chapters, the disclosure of information between doctor and patient has already been the subject of claims in negligence. This suggests negligence may be an appropriate vehicle for claims by family members injured by the nondisclosure of genetic risks.

If it is accepted that negligence is an appropriate means for remedying harm suffered by family members when genetic risk are not disclosed, the question becomes how the courts should construct a duty of care in these situations. It is trite that a duty must be considered 'from three perspectives, namely (a) foreseeability of the harm that ensues, (b) the natures of the relationship of the parties, usually called the element of proximity, and (c) the question whether it is fair just and reasonable that the law should impose a duty'.<sup>2</sup> The first of these 'perspectives' – harm – was considered within the genetic context in the preceding chapter. This chapter will explore the other key elements of the duty of care – proximity and whether it is fair, just a reasonable – and how these may apply to familial genetic risks.

### *Proximity and Neighbourhood*

Proximity – the inference of legal 'neighbourhood' – was described by Lord Atkin in *Donoghue* as existing when a claimant is 'so closely and directly affected by my acts that I ought reasonably to have them in contemplation as being so affected when I am directing

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<sup>1</sup> For example, in cases where the proband is identified as genetically at risk of pancreatic cancer, which is inoperable in 90 per cent of cases as a result of late diagnosis and only three per cent of patients survive beyond the five year mark.

<sup>2</sup> *Elgusouli-Daf v Commissioner of the Police of the Metropolis* [1995] QB 335 per Steyn LJ at 345.

my mind to the acts or omissions ... in question.’<sup>3</sup> A duty of care is not owed to the world at large and the courts have traditionally relied on physical closeness or antecedent relationships as indicators of sufficient proximity between parties, thereby controlling the scope of potential liabilities. However, neither physical nearness nor an antecedent relationship exist between the proband’s doctor and their blood relations and ‘it is plainly not sufficient’ that a doctor-patient relationship ‘exists between the defendant and [a] third party’.<sup>4</sup> It is therefore inadequate to demonstrate in isolation that a clinician’s failure to disclose genetic risks closely and directly affects the proband’s relatives. Claimants must also prove that they ought reasonably to have been ‘in contemplation as being so affected’.<sup>5</sup> In other words, the proband’s family must demonstrate that they are directly affected by, and identifiable victims of, the defendant’s negligence. The underlying reasoning for such a requirement was enunciated by Stuart-Smith LJ in *Palmer*, wherein he observed that ‘the most effective way of providing protection would be to give [a] warning’ and, where the victim is unidentifiable, ‘the most effective precaution cannot be taken because the defendant does not know who to warn.’<sup>6</sup> To construct a duty to disclose in terms which did not require the claimants to be identifiable would make such a duty difficult to discharge and could, in the extreme, expose the medical profession to a high number of claims. In conjunction with the necessity of a therapeutic response to the identified condition, a requirement that claimants are identifiable victims will impose a sensible limitation upon the scope of a duty to disclose, ensuring that it remains both a practicable and acceptable burden upon clinicians.

The concept of an identifiable victim/claimant was first explored by the New York Court of Appeals in *Palsgraf v Long Island Railway Co.*,<sup>7</sup> where the claimant sustained injury whilst waiting on the defendant’s railway platform. Negligence on the part of the station guards had resulted in a box of fireworks being dropped on the tracks. The fireworks exploded and the consequent shockwave dislodged a set of scales hung at the opposite end of the platform, which struck the claimant as they fell. One of the reasons the court dismissed the claimant’s action was because she was not an identifiable victim of the negligent act, Cardozo J concluding that a claimant must be able to establish ‘that the act

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<sup>3</sup> [1932] AC 562 at 580.

<sup>4</sup> *Palmer v Tees Health Authority* [2000] PIQR P1 *per* Stuart-Smith LJ at 12.

<sup>5</sup> *Donoghue v Stevenson* [1932] AC 532.

<sup>6</sup> *Palmer*, above, n 4, at 12.

<sup>7</sup> (1928) 248 NY 339.

as to him had possibilities of danger so many and so apparent as to entitle him to be protected against the doing of it though the harm was unintended.’<sup>8</sup>

Stuart-Smith LJ expressed a comparable opinion in *Palmer v Tees Health Authority*,<sup>9</sup> which concerned the abduction and murder of the claimant’s daughter by one of the defendant’s psychiatric outpatients, who had previously expressed having sexual desires towards children. He stated that in absence of direct contact between the parties ‘it is at least necessary for the victims to be identifiable ... to establish proximity’.<sup>10</sup> The Court of Appeal ultimately concluded that the claimant’s daughter was not an identifiable victim but a member of an indeterminate class of potential victims, which was insufficient to establish a relationship of proximity. A similar decision was expressed in *Bromley v United Kingdom*,<sup>11</sup> where the claimant’s daughter was an ordinary member of the public chosen at random by her murderer and, in *K v Secretary of State for the Home Department*,<sup>12</sup> a rape victim’s pre-trial application for disclosure under the Civil Procedure Rules was dismissed because the claimant could not ‘show that the Secretary of State should have been any more aware of her, as a potential victim ... that any other member of the public’.<sup>13</sup> When *K*’s negligence action against the Secretary of State reached the Court of Appeal, Laws LJ also concluded that there existed ‘no true nexus between claimant and defendant’.<sup>14</sup> The outcome differed in *W & Others* because the risk posed by the fostered boy to the family’s biological children was obvious and the victims were readily identifiable, therefore the possibility of abuse ought to have been within the defendant’s contemplation when placing the child with the family. The conclusions in *Tarasoff*, *Durflinger* and *Safer* were reached on a comparable premise. In each instance the ‘individual or group at risk is easily identifiable’,<sup>15</sup> either because the perpetrator had

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<sup>8</sup> *Ibid.*, at 345.

<sup>9</sup> [2000] PIQR P1.

<sup>10</sup> *Ibid.*, at 12.

<sup>11</sup> (Unreported) ECHR 23<sup>rd</sup> November 1999. The claimant’s daughter was murdered by a man who had failed to return to prison after home leave. The claim was struck out because the claimant could not satisfy either foreseeability or proximity. The European Court of Human Rights held that this did not amount to a violation of Art 6 ECHR.

<sup>12</sup> [2001] CP Rep 39.

<sup>13</sup> *Ibid.*, per Smith J (accessed online, pp. unavailable).

<sup>14</sup> [2002] EWCA Civ. 775 at 30.

<sup>15</sup> *Safer v Estate of Pack* 677 A 2d 1188 (New Jersey Court of Appeal) at 1192.

specifically identified them or through straightforward reference to degrees of consanguinity.

The question arising is therefore whether or not the proband's family are identifiable victims. Distinguishing the decisions in *Palmer*, *Bromley* and *K* because a family does not constitute a general, at risk class, and drawing upon *Tarasoff*, *Durflinger*, *Safer* and *W & Others*, it is apparent that the proband's family may be identifiable victims within the context of the nondisclosure of genetic risks as they are 'known to be at risk of ... harm from a genetically transmissible condition'.<sup>16</sup> Theoretically speaking, an entire family could share a deleterious genetic trait but the chances of a trait being shared are highest within the nuclear family. Beyond immediate blood relations, the gene pool diversifies, diluting the chances of a particular trait be inherited. Thus the chances of the proband sharing genetic risks with their cousin are appreciably lower than with their sibling. A patient's extended family are therefore less likely to be capable of establishing themselves as identifiable victims for the purposes of a duty to disclose, unless extremely compelling evidence to the contrary can be produced. Restricting any presumption about who constitutes an identifiable victim to the proband's nuclear family means that the scope of a duty to disclose remains manageable and, arguably, a justifiable burden upon clinicians. Although Mason and Laurie contend that distinguishing claims by 'straightforward reference to the degree of consanguinity' is 'an unsophisticated approach',<sup>17</sup> if a duty to disclose is to remain practicable it is a necessary control mechanism as seeking out and warning the various members of the proband's extended family 'might often be difficult or impractical and place a heavy burden upon the physician'.<sup>18</sup> The duty to disclose must be a justifiable imposition and it is arguably not so if it is so burdensome that it interferes with the actual provision of healthcare.

Of course, even if members of the proband's immediate family are identifiable victims, they must also demonstrate that they were closely and directly affected by the nondisclosure of the patient's genetic risks. This is arguably a straightforward causal exercise when the claimant is an identifiable victim, and will be satisfied where it is demonstrable that nondisclosure denied access to treatment. In this respect, consideration of proximity overlaps with the question of whether harm is foreseeable as there can be no

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<sup>16</sup> *Ibid.*

<sup>17</sup> Mason, J.K., Laure, G.T., *Mason & McCall Smith's Law and Medical Ethics*, 9<sup>th</sup> ed. (OUP, Oxford: 2013), p. 223.

<sup>18</sup> *Pate v Threlkel* 661 So 2d 278 (Supreme Court of Florida 1995) at 282. The burden may be reduced if patients are forthcoming with family information or the NHS achieves a centralised patient records system through the 'NHS Connecting for Health' project.

injury,<sup>19</sup> nor sufficient proximity, if there is no treatment available for the condition identified in the proband's genome. Therefore a proximate relationship would not exist if the proband has Huntington's disease because there is no treatment presently available, yet if the deleterious trait indicates cancer then treatment is available and a decision not to disclose will directly effect the proband's relatives because it denies them the opportunity to seek medical intervention. Moreover, as negligence is not assessed with the benefit of hindsight, any consideration of available treatments is primarily retrospective – temporally fixed at the time of the proband's test – although there must be latitude to take account of treatments that, whilst not currently available, will become so a reasonable time after the results are known.<sup>20</sup> However, there can be no duty to subsequently review the decision not to disclose, as it is necessary to impose 'some intelligible limits to keep the law of negligence within the bounds of common sense and practicality'.<sup>21</sup> To require clinicians to continuously review whether nondisclosure closely and directly affects the proband's immediate relatives is plainly too onerous a burden and inconsistent with public policy, the underlying force behind any assessment of proximity.<sup>22</sup>

#### *Fair, Just and Reasonable*

A determinative question in respect of any duty of care is whether it is fair just and reasonable to impose it. This aspect of the *Caparo* formula takes account of the policy factors that militate for and against the imposition of tortious liability in the given circumstances.<sup>23</sup> The policy issues at hand determine whether questions of foreseeability and proximity are construed restrictively or expansively and are fundamental in the creation of new duties of care. There are six policy issues relevant to a duty to disclose: doctor-patient confidentiality, psychiatric harm, the interest in not knowing, the vulnerability of family members, nonfeasance and the protection of the NHS.

#### *Doctor-Patient Confidentiality*

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<sup>19</sup> Since the adverse outcome that eventuates – the genetic condition – could not be avoided or minimised by disclosure.

<sup>20</sup> It is suggested here that a reasonable time would be no longer than six months after the date of the test.

<sup>21</sup> *Caparo Industries Plc. v Dickman* [1990] 2 AC 605 *per* Lord Oliver at 633.

<sup>22</sup> Hickman, T., 'Negligence and Article 6: the great escape?' (2002) CLJ 61(1) 13-17, p. 14.

<sup>23</sup> E.g. *Hill v Chief Constable of West Yorkshire* [1989] AC 53; *X & Others (minors) v Bedfordshire County Council* [1995] 2 AC 633, HL.



Confidentiality is ‘one of the cornerstones’ of the doctor-patient relationship.<sup>24</sup> Its origins lie in the Hippocratic Oath and its current ethical basis is the Declaration of Geneva, which obliges clinicians to ‘respect the secrets confided in them’.<sup>25</sup> A duty to disclose will – in effect – require a clinician to breach doctor-patient confidentiality, restricting the proband’s interests in the common law obligation to respect confidences, the Data Protection Act and Art 8 of the European Convention of Human Rights.

It is important to reiterate at this juncture that while there is overlap between confidentiality and privacy, the two concepts are not synonymous. As Laurie explains, confidentiality ‘is concerned as much with the protection of a relationship as with personal information’.<sup>26</sup> Privacy ‘requires no relationship and is concerned with the interests that encompass ... personal information’.<sup>27</sup> Moreover, the protection of health is a legitimate infringement of Art 8, although whether this restriction applies to personal health or public health is a moot point. What constitutes a legitimate restriction of confidentiality is, however, somewhat opaque. Although it is permissible to breach confidentiality and make a disclosure when it is in the public interest, what constitutes a public interest justification is context dependent. The uncertainties of the public interest defence were discussed at length in chapter two, alongside exceptions to data protection law, thus they will not be revisited in depth here. The same chapter made a case for justifying disclosing genetic information by reference to a public interest in preventing harm and Art 2 ECHR, thus a basis (potentially) exists for interfering with patient interests in confidentiality and data protection. A duty to disclose would be consistent with these public interests but also recognise the interests of the proband’s blood relations.

Although justifications for breaching confidentiality in this context do exist, it is important to recognise that any obligation to breach confidentiality may negatively affect the dynamic of the doctor-patient relationship, which, as Pattinson notes, ‘depends on trust.’<sup>28</sup> Rose J encapsulated these potential risks in *X v Y & Others*,<sup>29</sup> wherein he

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<sup>24</sup> Laurie, G.T., ‘Obligations arising from Genetic Information: Negligence and the Protection of Familial Interests’ (1999) 11 *Child and Family Law Quarterly* 109.

<sup>25</sup> General Assembly of World Medical Association (1948) as amended at Sydney (1968), Venice (1983) and Stockholm (1994).

<sup>26</sup> Laurie, G.T., *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge University Press, Cambridge: 2002) p. 211-212.

<sup>27</sup> *Ibid.*

<sup>28</sup> Pattinson, S.D., *Medical Law & Ethics*, 3<sup>rd</sup> ed. (Sweet & Maxwell, London: 2011), p. 201.

<sup>29</sup> [1988] RPC 379.

observed that without respect for medical confidentiality ‘doctors will be discredited ... for future patients will not come forward if doctors are going to squeal on them’.<sup>30</sup> The Court of Appeal differed somewhat in their conclusion in *W v Egdell*,<sup>31</sup> opining that in certain circumstances a doctor ‘owes a duty not only to his patient but also a duty to the public’,<sup>32</sup> which, in the context of *Egdell*, amounted to placing ‘before the proper authorities the results of his examination if, in his opinion, the public interest so required’.<sup>33</sup> The House of Lords subsequently delivered what is regarded as the leading ruling on confidentiality in *Attorney General v Guardian Newspapers (No. 2)*.<sup>34</sup> Their Lordships took the opportunity to explain that the legal foundation of confidentiality is ‘a public interest that confidences should be preserved’, but that the interest is not absolute and can ‘be outweighed by some other countervailing public interest which favours disclosure’.<sup>35</sup> The question therefore is whether the disclosure of genetic risks furthers a countervailing public interest and whilst it is irrefutable that avoiding or minimising harm or upholding Art 2 rights is in the public interest, the moot point is whether or not these interests incorporate the (mainly) personal interest in seeking medical intervention to avoid or minimise genetic risks.<sup>36</sup> Alternatively, disclosure could be argued as in the public interest if it improves access to healthcare or enables a greater number of individuals to receive therapies that might be – in comparison to invasive procedures – more cost-effective, thus influencing development of genomic medicine and the economic position of healthcare providers. For example, if drug therapies were to reduce the number of patients requiring chemotherapy by a quarter – and presuming these therapies proved to be more cost-effective than surgical intervention and chemotherapy – disclosure may fundamentally and positively affect the budgets of healthcare providers.

The issue for the courts to consider in the context of a duty to disclose is whether or not the disclosure of genetic risks is a justifiable restriction of doctor-patient confidentiality. If the public interest in avoiding harm and/or protecting Art 2 rights is interpreted as encompassing familial genetic risks, then it is suggested that limiting the

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<sup>30</sup> *Ibid.*, at 386.

<sup>31</sup> [1990] 1 All ER 835.

<sup>32</sup> *Ibid.*, at 852-853.

<sup>33</sup> *Ibid.*, at 853.

<sup>34</sup> [1990] 1 AC 109, HL.

<sup>35</sup> *Ibid.*, per Lord Goff at 282.

<sup>36</sup> This question was explored in greater depth in chapter two.

proband's interest in confidentiality is a justifiable measure. Furthermore, the international declarations and conventions produced thus far envisage some restrictions upon the rights of the proband. Art 26 of the European Convention of Biomedicine<sup>37</sup> states that the rights therein can be restricted 'for the protection of public health' and this qualification extends to the articles of its additional protocol on genetic testing in healthcare.<sup>38</sup> It is important to note that both the Convention and its additional protocol are couched in terms that are patient-centric, foregoing explicit mention of family interests in genetic information and risks. However, Art 16(4) of the protocol does acknowledge that in 'exceptional cases, restrictions may be placed by law on the exercise of the [proband's] rights', which may be read as including the prevention of injury to the proband's relatives from genetically transmissible conditions, although pedants will rightly note that whether such is an 'exceptional case' is a matter of perspective. UNESCO's Declaration on Human Genetic Data also acknowledges that the proband's interests are not without limit and permits nonconsensual disclosure 'for an important public interest reason in cases restrictively provided for by domestic law', and, on a broader legal spectrum, Art 8(2) ECHR lists 'the protection of public health' as a legitimate reason for restricting an individual's right to respect for privacy.

The GMC's 2009 guidelines on confidentiality suggests that the medical profession also recognises that doctor-patient confidentiality is not absolute, indicating that a patient's medical information may be disclosed without consent where a 'failure to disclose may expose others to risk of death or serious harm.'<sup>39</sup> However, whilst the guidelines do expressly address genetic information and risks, they provide little meaningful content, the guidelines simply directing clinicians to balance their duty of care to the patient against their duty to help protect others from serious harm.<sup>40</sup> The question here is how a balance is to be struck between these two duties and this is not addressed in the guidelines, which suggests the GMC considers it a matter of clinical judgement. The lack of content in the guidance may also be interpreted as unwillingness on the part of the GMC to provide a framework regarding the disclosure of genetic risks, beyond acknowledging that such information may need to be disclosed.

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<sup>37</sup> European Convention of Human Rights and Biomedicine (1997)

<sup>38</sup> Additional Protocol on the Convention of Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes (27<sup>th</sup> November 2008).

<sup>39</sup> General Medical Council, *Confidentiality: guidelines for doctors* (London, 2009), paragraph 53.

<sup>40</sup> *Ibid.*, paragraph 69.

The judiciary has previously been asked to strike a balance between competing interests in information. As discussed in chapter two, the courts have developed a line of case law concerning when confidential information may be disclosed, therefore this particular policy issue in creating a duty to disclose is not one with which the courts will be unfamiliar. In fact, it may be that the judiciary is one of the more appropriate bodies to adjudicate on confidentiality within this context because of its roots in the common law. American jurisprudence indicates that a carefully drawn duty to disclose can be balanced with doctor-patient confidentiality, with the latter retaining its traditional importance but yielding ‘to the extent that disclosure is essential to avert danger to others’.<sup>41</sup>

### *Psychiatric Harm*

Although it is argued throughout this thesis that disclosing information regarding the proband’s genetic risks to their immediate family has positive results, it is also recognised that ‘exposure to unsolicited information concerning future ill health, especially when nothing can be done to alleviate the condition, can result in significant mental trauma’.<sup>42</sup> Such a risk is clearly illustrated by the abortive attempt to screen newborns for alpha<sub>1</sub>-antitrypsin deficiency (A<sub>1</sub>AD) in Sweden between 1972-1974. A<sub>1</sub>AD is an autosomal recessive disorder caused by deficient production of alpha<sub>1</sub>-antitrypsin, a protein inhibitor produced in the liver that protects tissue (primarily in the lungs and liver) from the effects of the enzymes of ‘inflammatory cells’, which function to break down bacteria and host tissue. The condition typically manifests as asthma-like symptoms, such as wheezing, shortness of breath, rhonchi,<sup>43</sup> and rales;<sup>44</sup> in later life it can lead to emphysema, chronic obstructive pulmonary disease, degradation of lung tissue, cirrhosis, and liver failure. The aims of the Swedish programme were to (i) identify children with A<sub>1</sub>AD at an early stage; (ii) provide counselling to the parents regarding their child’s condition; and (iii) ‘to provide an opportunity to protect the affected children from concentrated air pollutants (mainly cigarette smoke), in the hope of preventing or postponing lung disease in adulthood’,<sup>45</sup> and

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<sup>41</sup> *Tarasoff v The Regents of the University of California* 529 P 2d 55 (Cal. 1974) *per* Justice Mathew O. Tobriner.

<sup>42</sup> Laurie, above, n 24.

<sup>43</sup> A coarse rattling sound as a person breathes – likened to snoring, wheezing, and (strangely) the sound of a donkey’s hooves as it runs – caused by mucus secretions in the bronchial airways.

<sup>44</sup> A clicking, rattling, or crackling noise made by a person’s lungs during inhalation when afflicted with a respiratory infection, typically detected by stethoscope.

<sup>45</sup> McNeil, T.F., *et al*, ‘Psychosocial Effects of Screening for Somatic risk: The Swedish a<sub>1</sub>-Antitrypsin Experience’ (1988) 43 *Thorax* 505, p. 505.

by the conclusion of the programme in 1974, 200,000 newborn babies had undergone screening for the relevant genetic markers.

Despite the commendable aims of the programme and considerable uptake, universal A<sub>1</sub>AD screening proved unsuccessful and was discontinued when follow-up studies indicated ‘that more than half of the families with affected children suffered adverse psychological consequences’.<sup>46</sup> The majority of parents ‘reacted negatively (usually with fear and anxiety) to the first news of the child alpha<sub>1</sub> deficiency’, these reactions ‘were typically strong and long lasting’ and, significantly, neonatal diagnosis did not ‘have a desirable effect on ... parental smoking’.<sup>47</sup> In fact, if anything, it increased it.<sup>48</sup> Furthermore, when a follow-up was conducted between 5 and 7 years after screening, approximately 50% of mothers and 33% of fathers were assessed by a psychiatrist as having made a poor to very poor emotional adjustment to their child’s condition. Mothers also ‘reported significantly poorer mental and physical health’.<sup>49</sup>

Potential psychological responses to the disclosing of genetic information represent a broad spectrum, ranging from anxiety to fear, guilt, depression, self-harm and, at the extreme, suicide. An international study conducted in 1999 found that the rate of suicides among individuals identified as possessing the genetic markers for Huntington’s disease is ten times greater than the national average for the United States.<sup>50</sup> The Danish Council of Bioethics has cautioned of the risk of disclosure of genetic risks leading to ‘morbidity’: ‘the notion of “falling victim” to some inescapable “fate” uncovered by genetic examination’.<sup>51</sup> However, the difficulties and respective failures must be contrasted with the success of neonatal screening for Duchenne’s muscular dystrophy (DMD) in Wales,<sup>52</sup> which suggests psychiatric harms flows as much from how the

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<sup>46</sup> Laurie, above, n 26, p. 124.

<sup>47</sup> McNeil *et al*, above, n 45 pp. 505-506.

<sup>48</sup> *Ibid.*, p. 506: ‘one or both of the parents smoked in more than half of the homes concerned; mothers of children with the deficiency smoked as frequently as control mothers, whereas fathers of these children smoked twice as frequently as control fathers’.

<sup>49</sup> *Ibid.*, p. 505.

<sup>50</sup> Almqvist, E., *et al*, ‘A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalization after predictive testing for Huntington’s disease’ (1999) 64 *Amer J Hum Gen* 1293. The results extrapolate to 138 per 100,000 compared to 12-13 per 100,000. The significance of the study was that it focused on the two years immediately after predictive genetic testing.

<sup>51</sup> Danish Council of Bioethics, *Ethics and Mapping the Human Genome* (Copenhagen, 1993), p. 60.

information is communicated and the support available as from the content of the information itself.

If – as discussed in the previous subsection – the public interest in preventing harm and Art 2 ECHR are accepted as favouring disclosure of genetic risks to blood relations, it follows that where the disclosure may cause psychological trauma it becomes inconsistent with these justifications. The question, therefore, is whether the risk of psychological harm is outweighed by the benefits of disclosing the proband's genetic information.<sup>53</sup> Once again this returns the analysis to the availability of treatments because, as Laurie explains, 'the availability of a cure carries with it the certainty that disclosure can incontrovertibly avert harm ... this can only be seen as a good thing for the third party to whom the disclosure is made.'<sup>54</sup> When a therapeutic response is available the risk of psychological harm being caused by disclosure is arguably outweighed by the possibilities of treatment. However, 'if the treatment is ineffective, painful or difficult to come by, the grounds are less firm'.<sup>55</sup> If disclosure were to be made in absence of treatment, perhaps with the aim of facilitating preparedness, then 'there is less of a guarantee that the harm in question will, de facto, be avoided'.<sup>56</sup> Therefore disclosure to persons with genetically transmissible conditions for which treatments are available may be justifiable even if there is a risk of psychological trauma, however, where the proband is identified as possessing genetic markers for an untreatable disease, the psychological risks of disclosure are not offset by the benefits of medical intervention.

It is therefore a necessity that treatment exists for the deleterious genetic traits identified if the imposition of a duty to disclose is to be fair, just and reasonable. In the absence of treatment, a duty may be imposed to engender preparedness, but arguments suggesting a duty to 'engender preparedness are suspect for the simple fact that it is far

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<sup>52</sup> See Parsons, E., Bradley, D., and Clarke, C., 'Disclosure of Duchenne Muscular Dystrophy after Newborn Screening' (1996) 74 Arch Dis Child 550.

<sup>53</sup> This balancing exercise appears to have all ready been countenanced by the courts: see *Re YZ* [2013] EWHC Fam 935.

<sup>54</sup> Laurie, above, n 26, p. 122.

<sup>55</sup> *Ibid.* A separate issue that arises within this context is how genetic information is communicated. For further discussion of genetic counselling and communication in neonatal testing see Fay, M., 'Negligence and the Communication of Neonatal Genetic Information to Parents' (2012) 20(4) *Med Law Rev* 604.

<sup>56</sup> Laurie, above, n 26, p. 122.

from clear that these ends are achievable, and indeed disclosure in such cases might lead to additional harms.<sup>57</sup>

### *The Right Not to Know*

It is axiomatic that some among the proband's relatives will not want to know about their family's genetic heritage. The possibility of psychiatric harm, or ethical, moral or religious factors may mean that some family members would rather not know about the proband's genetic information and, consequentially, their own. An interest in not knowing is recognised in Art 10(2) of the Convention on Biomedicine, which states that 'the wishes of the individual not to be informed shall be observed', and the additional protocol correspondingly states in Art 16(3) that '[t]he wish of a person not to be informed shall be respected'. UNESCO has also recognised a 'right' not to know in its Declaration on the Human Genome and Human Rights, wherein it is stated:

'The right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.'<sup>58</sup>

Both UNESCO's declaration and the Convention on Biomedicine adopt proband centric language, couching the interest in not knowing in terms of patient choice and rights, eschewing the interests that family members may have in not knowing about the proband's genetic risks. It is an interesting omission and one that is perpetuated by the GMC's confidentiality guidelines, which 'also ignores the possibility of relatives having an interest in not knowing'.<sup>59</sup> However, the right not to know may arise as an element of privacy under Art 8 ECHR, although there is no case in point.

The lack of a basis for a right not to know is problematic because whilst one is clearly envisaged, certainly in respect of the patient, it has not been sufficiently defined. As Chico explains, the interest in not knowing cannot be general – incorporating 'unknown unknowns', information that essentially lacks a degree of foreshadowing – because such 'would expose health professionals to liability on the basis of unpredictable individual evaluations of the desirability of the disclosure.'<sup>60</sup> In addition, Chico notes that

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<sup>57</sup> *Ibid.*, p. 261.

<sup>58</sup> Universal Declaration on the Human Genome and Human Rights, Art 5(c).

<sup>59</sup> Mason, Laurie, above, n 17, p. 224.

<sup>60</sup> Chico, V., *Genomic Negligence: an interest in autonomy as the basis for novel negligence claims generated by genetic technology* (Routledge-Cavendish, Abingdon: 2011), p. 177.

‘[p]ractically speaking, there cannot be a coexisting interest in knowing and an interest in not knowing’,<sup>61</sup> although she contends that an interest in not knowing could be recognised where an individual has previously indicated ‘in a way readily discoverable by health professionals, that she does not want to know information about her genetic risks.’<sup>62</sup> Equally, the interest in not knowing may be recognised and upheld where an individual is offered knowledge of genetic risks and rejects it. This latter scenario brings into question whether an interest in not knowing – in absence of a clear opt-in or opt-out – is practicable, because ‘in the very process of asking “Do you want to know whether you’re at risk...?” the geneticist has already made the essence of the information known’.<sup>63</sup> It has also been argued that the interest in not knowing is inconsistent with the courts’ continuing respect for personal autonomy as ‘to choose meaningfully we require full information about the range of options available and ... this paradigm breaks down in the context of an interest in not knowing’.<sup>64</sup> But if the courts are continuing to show respect for personal autonomy, why should they not recognise an autonomous decision to proceed in ignorance? Is the choice to know or not know (given that what is learned cannot be unlearned) any less meaningful in terms of personal autonomy than electing, on the basis of full information, to undergo one treatment over another?

Because the act of asking whether an individual wants to know about their genetic heritage may reveal the thrust of the information, to fully respect relatives’ interest in not knowing it may be necessary to operate on a presumption that family members do not wish to know about the proband’s identified risks. This approach is undesirable because it would undermine the extension to tort law proposed here: a duty to disclose would become superfluous if the default presumption is that everyone wishes to exercise their right not to know.

The Convention on Biomedicine and UNESCO’s declaration on Human Genetic Data appear to pursue a middle ground in this respect, permitting restriction of the ‘right’ contained therein for ‘the protection of public health’<sup>65</sup> and ‘an important public interest reason’.<sup>66</sup> If these restrictions are interpreted as applying only insofar as is necessary, then

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<sup>61</sup> *Ibid.*

<sup>62</sup> *Ibid.*, p. 179.

<sup>63</sup> Wertz, D.C., Fletcher, J.C., ‘Privacy and disclosure in medical genetics examined in an ethic of care’ (1991) 5 *Bioethics* 212, p. 221.

<sup>64</sup> Mason, Laurie, above, n 17, p. 225.

<sup>65</sup> European Convention on Human Rights and Biomedicine (1997), Art 26(1).

<sup>66</sup> Universal Declaration on Human Genetic Data, Art 14(b).



the question is not which is the overreaching interest but – as with doctor-patient confidentiality – how to achieve an effective balance between two competing interests. In other words, if the public interest is in avoiding harm, then the private interest in not knowing may yield only insofar as is necessary to avoid or minimise the predicted harm and, thereby, uphold the public interest. In the context of genetic risks, harm can be avoided or minimised by providing information on the proband's genetic risks and inviting family members to seek testing; thereafter, relatives can either undergo testing or assert their right not to know.

Studies that have investigated the acceptability of disclosing genetic information to family members support such an approach to balancing the interests in knowing and not knowing. A 2006 study in Australia found that family members did not consider it a breach of privacy nor autonomy to receive a letter disclosing that they may be genetically at risk of cancer, even when respondents declined to receive any further information.<sup>67</sup> Moreover, it was found that when clinicians disclosed the presence of genetic risks the uptake of genetic testing was double (46 per cent) that when no contact was attempted (23 per cent), or where contact was attempted indirectly through a letter to be delivered by the proband (26 per cent).<sup>68</sup>

It is axiomatic that an individual's ability to control the information they receive is an important aspect of personal autonomy and privacy, yet a balance must be struck with the countervailing public interests that may favour disclosure of genetic risks. Studies are indicative that disclosure by clinicians will lead to an increase in the uptake of genetic screening, which, in turn, will lead to an increase in the accessibility of preventative therapies or early medical intervention and, potentially, furthers the pursuit of the public interests in avoiding harm and protecting Art 2 rights. If, however, no treatments are available for a particular condition then the public and private interests align, as the harm that can potentially be avoided is psychiatric. Of course, in this latter scenario, the duty to disclose would not be engaged because no treatment exists and therefore nondisclosure does not cause the claimant harm.

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<sup>67</sup> Suthers, G.K., *et al*, 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder' (2006) 43 *J Med Genet* 665. Of 351 family members contacted, 25 respondents indicated a wish not to receive any further information.

<sup>68</sup> The focus of this thesis is on whether a duty to disclose genetic risks ought to be owed to the proband's immediate family, but equally important questions arise in respect of when and in what manner this information should be imparted. For example, on the role of genetic counselling in neonatal screening and possible liabilities therein, see Fay, M., 'Negligence and the communication of neonatal information to parents' (2012) 20(4) *Med Law Rev* 604.

### *The Vulnerability of Family Members*

As Mulheron writes, family members ‘at risk of manifesting diseases are vulnerable’.<sup>69</sup> This is because

‘generally they have to rely upon HCPs who are in a stronger position *by virtue of the information* that they possess about the diseased patient, and about which the non-patient knows nothing and cannot ascertain for himself.’<sup>70</sup>

In the Australia case of *BT v Oei*,<sup>71</sup> the claimant’s sexual partner was infected with HIV but his physician did not competently diagnose him. The claimant was thus exposed to a risk of contracting HIV due to the clinician’s negligence. The claimant was vulnerable in this instance because she had no way of ascertaining for herself that her partner was HIV positive, therefore the clinician was held to owe her a duty of care. In *Bradshaw v Daniels*,<sup>72</sup> a clinician was held to owe a duty of care to warn a patient’s wife of the risks of exposure to the source of her husband’s non-contagious disease (Rocky Mountain spotted fever) because she had the same epidemiological risk. Parker argues that the claim by the wife’s estate succeeded because ‘the relationship puts the physician in a position to know of a risk that may not be obvious to others’,<sup>73</sup> although it is important to note that the court did not express their judgment in such terms.

In the context of the nondisclosure of genetic risks, the patient’s family are not placed in harms way as in *BT*, where the clinician’s negligence put the claimant at risk of contracting HIV. By contrast, genetic risks cannot be contracted and, as has been previously indicated, the nondisclosure is not the root of the disorder. Instead the proband’s family are vulnerable because, post genetic screening, clinicians will possess information that is indicative of risk to their long-term health. If a clinician does not disclose genetic information and a family member goes on to develop the identified condition, then they occupy a similar position to the claimant in *Bradshaw*, in that, had they been warned of the risk, they could have sought preventative therapies or earlier

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<sup>69</sup> Mulheron, R., *Medical Negligence: Non-Patient and Third Party Claims* (Ashgate: Farnham, 2010), p. 135.

<sup>70</sup> *Ibid.*

<sup>71</sup> [1999] NSWSC 1082.

<sup>72</sup> 854 WE 2d 865 (Tenn. 1993)

<sup>73</sup> Parker, C., ‘Camping trips and family trees: must Tennessee physicians warn their patient’s relatives of genetic risks?’ (1998) 65 *Tennessee L Rev* 585, p. 597.

treatment. Therefore, when considering the policy issues relevant to a duty to disclose, it is necessary to take account of the vulnerable position of the proband's immediate relatives. In the circumstances presented here, where treatments are available for a condition and a clinician is aware of a familial risk, a patient's relatives will be vulnerable to a condition that may otherwise be avertable (or manageable) if no disclosure is made. This was precisely the circumstance that arose in *Safer*,<sup>74</sup> where the clinician did not disclose the hereditary nature of his patient's cancer, which the patient's daughter, unaware of the risk, went on to develop. It was judged in that case that, had a timely disclosure been made, the claimant's cancer could have been averted or minimised.

### *Nonfeasance*

It is a general principle of English tort law that a person is not liable for a failure to act. As Lord Keith explained in *Yuen Kun Yeu v Attorney General of Hong Kong*,<sup>75</sup> there is no 'liability in negligence on the part of one who sees another about to walk over a cliff with his head in the air and forebears to shout a warning'.<sup>76</sup> Liability can arise for omissions in limited circumstances but, in the context of genetic risks, it is axiomatic that the defendant has not created the source of the risk,<sup>77</sup> nor assumed responsibility for the welfare of family members.<sup>78</sup>

The line between misfeasance and nonfeasance can, however, be somewhat difficult to draw. Thus what may originally appear to be an omission may actually be treated as a positive act by the courts. The exemplar here is the conduct of the driver who fails to break for a red light, which can be phrased both as an omission and a positive act.<sup>79</sup> The nondisclosure of genetic information may therefore be treated as misfeasance as opposed to nonfeasance, however, it is more likely to be viewed as an omission, analogous to the actions of the priest and the Levite who passed the traveller by: 'an omission which was likely to have as its reasonable and probable consequences damage to health ... but for

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<sup>74</sup> *Safer v Estate of Pack* 677 A 2d 1188 (New Jersey Court of Appeal).

<sup>75</sup> [1982] AC 175.

<sup>76</sup> *Ibid.*, at 192.

<sup>77</sup> See *Rigby v Chief Constable of Northamptonshire* [1985] 1 WLR 1242; *Knightly v Johns* [1982] 1 WLR 349.

<sup>78</sup> See, for example, *Kent v Griffiths* [2001] QB 36; *Jebson v Ministry of Defence* [2000] 1 WLR 2055; *Barrett v Ministry of Defence* [1995] 1 WLR 1217.

<sup>79</sup> See *Kelly v Metropolitan Ry Co* [1895] QB 944; also *Barnett v Chelsea & Kensington Hospital Management Committee* [1969] 1 QB 428.

which the priest and the Levite would have incurred no civil liability in English law'.<sup>80</sup> The question therefore is why should a clinician owe a duty of care to the proband's immediate family when the conduct complained of is potentially an omission?

The answer, it is suggested, is because clinicians, by virtue of the proband's genetic test, have specific knowledge of the prospective risks to long-term health of the patient's family. In *Stovin v Wise*,<sup>81</sup> Lord Hoffmann observed that

'[a] duty to prevent harm to others or to render assistance to a person in danger or distress may apply to a large and indeterminate class of people who happen to be able to do something'.<sup>82</sup>

His Lordship then posed the perennial question: '[w]hy should one be liable and not another?'<sup>83</sup> The risk of indeterminate liability militates against a general duty to render assistance. However, in the context of genetic risks, knowledge of the risks and therefore the capacity to 'do something' are not applicable to an indeterminate class. Instead, the proband's genetic test results will be restricted to a finite group of medical practitioners. Therefore, drawing upon the decisions in *Tarasoff*, *Durflinger*, *Palmer* and *W & Others*, clinicians will have specific knowledge of risks to an identifiable group of victims, which is not available to the population at large. Consequentially it is suggested that nondisclosure is capable of amounting to negligence because no one else, with the exception of the proband, is capable of disclosing genetic information to family members.<sup>84</sup>

Knoppers, however, argues that judgments such as *Tarasoff*, *Durflinger* and *Palmer* offer little in terms of guidance regarding nondisclosure of genetic risks because:

'it is a patient's actions which are likely to harm others in the case of a threat of violence, in the case of genetic conditions, the patient is not putting relatives at risk

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<sup>80</sup> *Home Office v Dorset Yacht Co Ltd* [1970] AC 1004 *per* Lord Diplock at 1060.

<sup>81</sup> [1996] AC 923.

<sup>82</sup> *Ibid.*, at 944.

<sup>83</sup> *Ibid.*

<sup>84</sup> The effectiveness of the proband as a conduit for disclosure is open to debate. See Suthers, G.K., above, n 67. A duty to disclose could also be imposed upon the proband but this is ethically questionable: see Laurie, G.T., above, n 24.

by carrying the gene mutation because the relatives already have the mutation or not'.<sup>85</sup>

This is arguably a narrow view, which ignores that these cases are examples of situations where the defendant 'is privy to important information through the medium of a patient which could be used to protect third parties from harm'.<sup>86</sup> Furthermore, aside from the patients themselves, the defendant institutions were the only other party privy to the risks facing the victims. Whether or not the victims were identifiable was crucial in this regard. In *Tarasoff* and *Durflinger* a duty of care was imposed because the defendant's failure to disclose caused harm to an identifiable victim, whereas the appeal in *Palmer* was dismissed because the omission posed a risk to a general class and it was not possible to give an effective warning.

It is therefore suggested that when the defendants have specific knowledge of a risk to an identifiable victim, a duty of care can exist in respect of the omission to disclose because the ability to 'do something' is restricted to a finite group of medical professionals, therefore circumventing the risk of indeterminate liability which generally discourages the imposing of duties in respect of nonfeasance.

### *Protecting the NHS*

Another policy consideration that may weigh upon the court's mind when assessing a duty to disclose is the protection of the National Health Service (NHS). It is foreseeable that genetic screening will be offered through the NHS, therefore a question arises about whether a duty to disclose would open the proverbial floodgates and expose the NHS to a high volume of litigation.

This policy consideration is linked with the problem of indeterminate liability discussed in relation to nonfeasance and it has all ready been explained why this is not a prohibitive issue in relation to genetic screening. However, the courts may also consider the potential impact of a legal duty on genetic medicine and screening within mainstream healthcare. It is possible that a duty to disclose could engender defensive practice, dissuading clinicians from offering genetic screening to their patients because they are unwilling to expose themselves to potential liabilities. Alternatively, the NHS, in general, may be unwilling to risk depleting its finite budget through litigation and could, as a result,

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<sup>85</sup> Knoppers, B., *et al*, 'Professional disclosure of Familial Genetic Information' (1998) 62 *Am J Hum Genet* 474-484, p. 481.

<sup>86</sup> Laurie, above, n 24.

restrict the availability of genetic screening. Either scenario would effectively neuter the development of clinical genetics, which is an undesirable outcome.

Although these are *prima facie* valid concerns, they do not withstand close scrutiny. The purpose of a duty to disclose is to engender disclosure of genetic information to members of a patient's immediate family when a treatment is available for the disorder in question. By limiting the duty's scope to identifiable claimants, the obligation is not too burdensome. This was the position in *Safer v Estate of Pack*, where it was felt that persons at risk of genetically transmissible diseases were readily identifiable and contacting these persons did not place too burdensome an obligation upon the clinician. Furthermore, in this form the duty is dischargeable through the provision of a warning of the identified genetic risks to those most likely to share those deleterious traits. The only point at which clinicians would be exposing themselves to liabilities would be when they did not disclose treatable risks to the proband's immediate family, thus there will be only a small number of potential claimants in any one case. Furthermore, as liability is contingent on the genetic condition manifesting and not all relatives will develop the condition, the number of potential claimants is greater than those who will have a valid claim against the clinician. A final point is that despite creation of the *Tarasoff*-type duty and the extension of this to genetic risks, there is no available evidence of high levels of defensive practice in the US.

The concern in respect of the NHS budget is also unconvincing because encouraging disclosure and, thereby, uptake of early intervention or preventative therapies may be in the economic interest of healthcare providers. Careful consideration of the economics of disclosure is warranted before it can be definitively claimed that there are financial benefits, but there is evidence underlining the potential gains. An example of the potential positive economic impact is tamoxifen, which the NHS plans to offer to woman at risk of breast cancer following the release of guidelines by the National Institute of Clinical Excellence.<sup>87</sup> The drug is relatively inexpensive, costing approximately £130 for a five-year course, which compares to an annual cost of breast cancer treatment of around £12,000.<sup>88</sup> If healthcare providers were to effectively discharge their duty, and patient's relatives act on the information provided – which is more likely if a clinician makes the disclosure – the economics of the situation may work in the favour of institutions like the NHS and not lead to litigation that will place additional strain on their finite budgets.

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<sup>87</sup> BBC News, 'Breast cancer: NHS to offer tamoxifen to at-risk women' 25 June 2013.

<sup>88</sup> *Ibid.*

An argument based upon an opening of the floodgates or inhibiting the development of genetic medicine does not, therefore, appear a convincing reason to refuse to create a duty to disclose.

### *Conclusion*

The shared nature of genetic information means that tensions will inevitably arise between a clinician's duty of confidentiality to the proband and the potential to avert harm to immediate members of their family. Disclosure of genetic risks may allow individuals to seek preventative therapies or to undergo prompt treatment and – as genetic screening is increasingly integrated into mainstream healthcare – the traditional paradigm of doctor-patient relationships will become an increasingly difficult to sustain. The important question is how to balance the interests of patients and their immediate family when it comes to genetic risks. It is suggested that the tort of negligence could be extended and a duty to disclose developed, providing a clear indication of when genetic risks should be disseminated beyond the doctor-patient relationship and to whom. In order to establish sufficient proximity, it will be necessary for the claimants to establish themselves as identifiable victims who are closely and directly effected by the nondisclosure, which, it is suggested, will limit liability to immediate relatives unless members of the proband's extended family can raise compelling reasons to the contrary. In respect of the third limb of the *Caparo* test – whether it is fair, just and reasonable to impose a duty of care – a number of policy issues have been identified and considered. It has been argued that none represent a barrier to liability for nondisclosure but it remains necessary to impose 'some intelligible limits to keep the law of negligence within the bounds of common sense and practicality'.<sup>89</sup> This need for limits again returns to the crux of the argument: that treatment has to be available for the disorder in question if a duty to disclose is to arise.

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<sup>89</sup> *Caparo Industries Plc v Dickman* [1990] 2 AC 605 per Lord Oliver at 633.

## **6. BREACH OF DUTY AND A DUTY TO DISCLOSE**

### *Introduction*

It has been proposed in the proceeding chapters that a healthcare practitioner should owe a duty to disclose genetic information – specifically risks of disease – to the blood relations of the proband. If a duty is established between clinician and family members, the next question is how the courts should assess breach. The answer is not straightforward because medicine is an inexact science, which incorporates a significant amount of discretion, and the courts have recognised this through refusing to hold a healthcare practitioner negligent simply because another would have acted differently in the circumstances. In the context of disclosing genetic risks, the traditional approach to breach in clinical negligence claims is capable of incorporating both disclosure and nondisclosure as non-negligent behaviour providing both are backed by a responsible body of medical opinion. Effectively such a conclusion empties a duty to disclose of content, since a failure to disclose a genetic risk would not constitute a negligent act. A more nuanced approach to breach is therefore necessary if the proposed duty is to have any value.

The starting point is what should constitute a breach of duty in the context of not disclosing genetic information. A simplistic (and unhelpful) answer is the act of failing to disclose information pertaining to genetic risks. However, a breach of duty is not merely an act but an act which falls below the appropriate standard for the given circumstances. Therefore it is not sufficient that a healthcare practitioner fails to disclose a genetic risk, doing so must constitute a failure to uphold the appropriate standard of care if the law is to recognise such an act as a breach of duty.

The issue of breach in medical negligence has traditionally been assessed with the test from *Bolam v Friern Hospital Management Committee*,<sup>1</sup> which draws upon the testimony of responsible bodies of medical opinion to determine whether the defendant's conduct is below the appropriate professional standard for the situation. The so-called *Bolam* test is thus a starting point for the assessment of breach in the context of the nondisclosure of genetic risks. Application of the *Bolam* test simpliciter is, however, problematic. This is because absent a unilateral policy regarding the disclosure of genetic risks, it is possible for both disclosure and nondisclosure to be supported by opposing bodies of medical opinion and the courts are reluctant to conclude a practice is negligent because an alternate exists. Therefore if a duty to disclose is to have content it is necessary for the courts to move beyond the *Bolam* test. One potential avenue is to apply the

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<sup>1</sup> [1957] 1 WLR 582



qualification to *Bolam* in *Bolitho v City & Hackney Health Authority*.<sup>2</sup> In *Bolitho* it was said that a body of medical opinion supporting a contested practice must be capable of withstanding ‘logical analysis’<sup>3</sup> and failure to do so would be evidence of a breach of duty. The question, however, is what is actually meant by ‘logical analysis’ since varying interpretations have been advanced, including a test of reasonableness and an analysis of the risks and benefits inherent in a particular conduct.

The unavoidable necessity of recognising clinical discretion may mean that applying the *Bolam* test to nondisclosure of genetic risks is impractical and thus an alternative means of assessing breach must be sought. A potential alternative to *Bolam* may be drawn from claims concerning the nondisclosure of medical risks, which have gravitated away from a standard of care based upon responsible medical opinion. Instead, breach in these cases is assessed by reference to what a reasonable patient would want to know in the circumstances. In the context of the nondisclosure of genetic risks, it is possible that a modified form of the reasonable patient approach might be a more appropriate test of breach than *Bolam*, particularly if a unilateral opinion on disclosure is lacking. However, the longstanding nature of the *Bolam* test means it cannot be discounted as a method for assessing breach, therefore both potential approaches and how these may apply in claims concerning a duty to disclose must be considered.

### *Bolam*

The case of *Bolam* concerned an application of electroconvulsive therapy without the administration of a relaxant drug or the use of physical restraints, the consequences of which were that the patient’s involuntary movements while undergoing the therapy caused him serious injuries, including a fractured pelvis. The patient sued alleging that the lack of use of restraints or relaxant amounted to negligence but the court held that no breach of duty had occurred. The defendant had acted in accordance with ‘a practice accepted as proper by a responsible body of medical men skilled in that particular art’,<sup>4</sup> thus his actions had not fallen below the appropriate standard of care in the given circumstances.

The crux of the *Bolam* test is that a clinician delivering treatment in a way that is practiced (or considered acceptable practice) by others in their field is not negligent, even if an alternate school of thought exists unless ‘it [the practice] has been proved contrary to

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<sup>2</sup> *Bolitho v City & Hackney Health Authority* [1998] AC 232.

<sup>3</sup> *Ibid.*

<sup>4</sup> *Bolam*, above, n 1, per McNair J at 587.

what is really substantially the whole of informed medical opinion.’<sup>5</sup> In this way the *Bolam* test accounts for the fact that medicine is an inexact and an ever-changing science incorporating a strong element of discretion. A clinician could not conduct surgery using eighteenth century practices – such as forsaking anesthetics and antiseptics<sup>6</sup> – but they would not be precluded from pursuing one course of conduct merely because an alternate body of opinion existed. Therefore in *Bolam* the doctor’s conduct – conducting electroconvulsive therapy without restraints or relaxant drugs – was not negligent simply because another body of opinion favoured an alternate approach.

In the subsequent judgment of *Maynard v West Midlands Regional Health Authority*<sup>7</sup> the House of Lords reiterated that ‘in the realm of diagnosis and treatment negligence is not established by preferring one respectable body of professional opinion to another’.<sup>8</sup> For a breach of duty to be established there has to be evidence that the clinician’s conduct fell below the appropriate standard of care accepted in their area of practice, not that he or she acted in accordance with a body of medical opinion with which the judge does not agree.

Thus the *Bolam* test poses something of a conundrum in respect of genetic information. The assessment of breach accounts for clinical discretion and divergent opinion, meaning negligence is not proven because there existed an alternative approach to the problem at hand. For this reason the *Bolam* test is unlikely to be sympathetic to the proband’s blood relations where a genetic risk has not been disclosed. The discretionary element of *Bolam* means that providing a responsible body of medical opinion supports nondisclosure, it is a justifiable response to the circumstances. The courts would only be likely to reject medical opinion supporting nondisclosure if such is ‘contrary to what is really substantially the whole of informed medical opinion’ and the difficulty here is that there is no clear agreement regarding disclosure. Research on the opinion of medical geneticists in America illustrates the issue.<sup>9</sup> Although in excess of two thirds of respondents felt they bore responsibility for warning blood relations of genetic diagnosis, and a quarter considered disclosing information when the proband refused, only a minority

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<sup>5</sup> *Ibid.*

<sup>6</sup> *Ibid.*

<sup>7</sup> [1985] 1 All ER 635.

<sup>8</sup> *Ibid.*, per Lord Scarman at 639.

<sup>9</sup> Falk, M.J., Dugan, R.B., et al, ‘Medical geneticists duty to warn at risk relatives for genetic disease’ (2003) 120 Am J Med Genet 374.

actually did.<sup>10</sup> The core reasons for nondisclosure were presented as emotional issues, confidentiality and legal liability. It is extremely difficult – if not nigh impossible – to argue that refusing to disclose information pertaining to a patient because of doctor-patient confidentiality is against informed medical opinion – it is, after all, in the public interest to preserve confidences – which returns us to the importance of identifying a countervailing public interest that favours disclosure.<sup>11</sup>

Unless a ‘joint account’<sup>12</sup> approach to healthcare and, specifically, genetic information is adopted or consensus is achieved with respect to disclosure, claimants will find it difficult to demonstrate a breach of duty. The significance of doctor-patient confidentiality in medical practice – and the diverse opinions regarding reconciliation with genetic information<sup>13</sup> – means that consensus on disclosure will be difficult to achieve. And, as Lord Scarman explain in *Maynard*, where two bodies of medical opinion exist, advocating opposite courses of action:

‘a judge’s “preference” for one body of distinguished professional opinion to another also professionally distinguished is not sufficient to establish negligence ... Failure to exercise the ordinary skill of a doctor (in the appropriate specialty, if he is a specialist) is necessary.’<sup>14</sup>

Mason and Laurie explain that, in this way, ‘*Bolam* provides some protection for the innovative or minority opinion or, indeed, the individual clinical judgement call’.<sup>15</sup> The refusal of the judiciary to attribute negligence based upon a preference for one body of opinion over another is laudable, in one respect, as it permits clinical practice to develop and diversify without fear that innovation will amount to negligence because it departs from established practice. If the courts were unwilling to accept divergent opinions there would be a serious risk that clinical development would be stymied by legal interference,

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<sup>10</sup> *Ibid.*

<sup>11</sup> See chapter two.

<sup>12</sup> Parker, M., Lucassen, A., ‘Genetic Information: A Joint Account?’ (2004) *BMJ* 329 165-167, p. 166.

<sup>13</sup> See chapter two.

<sup>14</sup> *Maynard*, above, n 7, *per* Lord Scarman at 639.

<sup>15</sup> Mason, J.K., Laurie, G.T., *Mason & McCall-Smith’s Law and Medical Ethics*, 9<sup>th</sup> ed. (OUP: Oxford, 2013), p. 139. See also *Zarb v Odetoyinbo* (2007) 93 BMLR 166 concerning the ‘individual clinical judgement call’.

which is disadvantageous to patients in the long-term because new therapies would not be pioneered.<sup>16</sup> For example, it would be unlikely that genomic medicine and (in years to come) gene therapies would be integrated into mainstream healthcare if departure from established medical practice amounted to proof of negligence.

Yet at the same time the courts can be justly criticised for adhering to the *Bolam* test. The strongest criticism of the approach is that it engenders a paternalistic approach to medical negligence claims by permitting a defendant's contemporaries to determine the appropriate standard of care attributable to the circumstances.<sup>17</sup> A paternalistic approach is not to be portrayed as a universal negative, however, as it offers a degree of legal protection to pioneering clinicians who may otherwise be found negligent because they deviate from the accepted norm.<sup>18</sup> Yet it is undeniable that the medical profession is able to exert an influence upon the law through reference to common practice that other defendants – for example, motorists<sup>19</sup> – are not. Critics 'have persistently argued that doctors themselves should not dictate whether conduct is negligent; this should be a matter for the courts.'<sup>20</sup> The judiciary, on occasion, has made a comparable point<sup>21</sup> and, in other commonwealth jurisdictions, the courts have departed from a profession-reliant test for breach of duty.<sup>22</sup>

The paternalistic nature of *Bolam* is an important element in the problem it will pose in respect of nondisclosure. Although the courts willingness to account for clinical

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<sup>16</sup> For example, see *De Freitas v O'Brien* [1995] 6 Med LR 108, CA. The case concerned a spinal surgeon described as one of only eleven such specialists in the UK.

<sup>17</sup> Teff, H., *Reasonable Care* (OUP, Oxford: 1994).

<sup>18</sup> For further discussion of paternalism and the margin of appreciation in medicine, see Foster, C., *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Hart, Oxford: 2009) and Tallis, R., *Hippocratic Oaths: Medicine and its Discontents* (Atlantic Books, London: 2004).

<sup>19</sup> I.e. failing to indicate before turning off a roundabout may be common practice but it would always constitute negligence were it to cause an avoidable accident.

<sup>20</sup> Mason, Laurie, above, n 15, p. 138.

<sup>21</sup> See Lord Irvine (then Lord Chancellor) 'The patient, the doctor, their lawyers and the judge: rights and duties' (1999) Med L Rev 255, *Smith v Tunbridge Wells Health Authority* [1994] 5 Med LR 334 and, in the commonwealth, *Reibl v Hughes* (1980) 114 DLR (3d) 1 and *Rogers v Whittaker* (1992) 109 ALR 625.

<sup>22</sup> Most notably, the High Court of Australia in *Rogers v Whittaker*, *ibid.*, at 631: 'it has been accepted that the standard of care to be observed by a person with some special skill or competence is that of an ordinary skilled person exercising and professing that special skill. But that standard is not determined solely or even primarily by reference to the practice followed or supported by a responsible body of opinion in the relevant profession or trade.'

innovation and discretion is not necessarily a negative, their reluctance to judge opposing bodies of medical opinion means both nondisclosure and disclosure are potentially justifiable responses to the identification of a prospectively shared genetic risk. This is dependent on each being consistent with responsible bodies of medical opinion, but that is not unforeseeable. The problem with this outcome is that it could empty a duty to disclose of content, for providing nondisclosure finds support in a responsible body of medical opinion, existence of a countervailing opinion does not demonstrate negligence. The reasons medical geneticists have elected not to disclose<sup>23</sup> – which are only examples of the justifications for nondisclosure – are difficult, if not impossible, to portray as being contrary to informed medical opinion. Thus *Bolam* could render a duty to disclose legally superfluous because a defendant's conduct is unlikely to constitute a breach of duty.

### *Bolitho*

The problems posed by the *Bolam* test mean that an alternate method for scrutinising breach is necessary if the duty to disclose is to possess any legal value, otherwise it will be a hollow shell of an obligation. There are two approaches the courts could potentially adopt to avoid this outcome. This thesis will return to the assessment of breach in doctor-patient disclosure cases further below. The immediate question will be whether the House of Lords decision in *Bolitho v City & Hackney Health Authority*<sup>24</sup> could be applied to prevent a duty to disclose being emptied of content. The judgment in *Bolitho* is 'regarded by some commentators as representing a significant nail in *Bolam*'s coffin'<sup>25</sup> and 'initially thought to be the missing link in the standard of care in clinical negligence cases which would pave the way for the courts to reject medical opinion if it could not withstand "logical scrutiny".'<sup>26</sup> Thus the crucial question becomes not whether nondisclosure is consistent with a responsible body of medical opinion, but whether nondisclosure when treatment is available – and any opinion supporting such conduct in these circumstances – can be rejected for not withstanding logical analysis.

*Bolitho* arose from a failure to intubate a child suffering respiratory arrest, which ultimately led to the child's death. The defendant had failed to attend the child during this time and it was accepted that such conduct was negligent. It was accepted that intubation

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<sup>23</sup> Falk, Dugan, above, n 9.

<sup>24</sup> [1998] AC 232.

<sup>25</sup> Mason, Laurie, above, n 15, p. 139.

<sup>26</sup> Heywood, R., 'The Logic of Boltho' (2006) 22(4) PN 225, p. 225.

would have alleviated the child's condition and his death would then not have occurred, yet it was contested by the defendants that had the clinician attended the child she would not have elected to intubate and thus her negligence did not cause the child's death. The doctor's proposed action (i.e. the non-intubation) was supported by a responsible body of medical opinion and, despite the 'hypothetical and self-serving nature'<sup>27</sup> of the defendant's evidence, the House of Lords concluded that the health authority was not liable for the child's death, the decision reinforcing the earlier point from *Maynard* that a finding of negligence is not satisfied merely because a preferable body of medical opinion exists. However, their Lordships introduced an important caveat to the established elements of the *Bolam* test, explaining that while

'in the vast majority of cases the fact that distinguished experts in the field are of a particular opinion will demonstrate the reasonableness of that opinion ... if, in a rare case, it can be demonstrated that the professional opinion is not capable of withstanding logical analysis the judge is entitled to hold that the body of opinion is not reasonable or responsible.'<sup>28</sup>

The decision represents a judicial restatement of the court's role as final arbiters of what constitutes negligence and commentators have argued that it 'undoubtedly devalues the trump card which *Bolam* presented to the medical profession',<sup>29</sup> although it is recognised that this is 'only in limited circumstances'.<sup>30</sup> But for all its heralded importance,<sup>31</sup> the level of impact *Bolitho* has had in cases concerning the standard of care in medical practice is limited, although the number of cases in which *Bolitho* has been invoked is 'not quite so low as to be labelled "rare"'.<sup>32</sup> The limited impact demonstrates a continued reluctance on the courts behalf to question the evidence of medical professionals. In the context of genetic risks and disclosure, any argument drawing upon *Bolitho* must be made with caution because 'logical analysis' appears to be an exception rather than a necessity.

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<sup>27</sup> Jones, M., 'The Bolam Test and the Reasonable Expert' (1999) 7 Tort Law Rev 226.

<sup>28</sup> *Bolitho*, above, n 24, *per* Lord Browne-Wilkinson at 243.

<sup>29</sup> Mason, Laurie, above, n 15, p. 139.

<sup>30</sup> *Ibid.*

<sup>31</sup> For example, see Grubb, A., 'Negligence: Causation and *Bolam*' (1998) 6 Med L Rev 378; Brazier, M., Miola, J., 'Bye-bye *Bolam*: A Medical Litigation Revolution?' (2000) 8 Med L Rev 85.

<sup>32</sup> Mulheron, R., 'Trumping Bolam: a critical legal analysis of *Bolitho*'s "gloss"' (2010) 69(3) CLJ 609, p. 610.

Research by Maclean in *Bolitho*'s formative years found – between 1998 and 2001 – 64 litigated cases concerning standard of care, with *Bolitho* referenced in 25 first instance decisions and four Court of Appeal hearings. Those figures would indicate that '*Bolam* is far from dead'<sup>33</sup> and suggest *Bolitho* has not fundamentally altered the principles governing breach in medical negligence claims. More than a decade on, the number of cases applying *Bolitho* is 'not quite so low as to be labelled "rare"',<sup>34</sup> and the courts appear 'increasingly determined that the *Bolam* principle is not extended',<sup>35</sup> but there continues to exist a reluctance to abandon *Bolam* in respect of medical opinion.<sup>36</sup> There is 'a sense that *Bolitho* ... is being used as a "back-up" position', though *Bolam* can no longer be regarded as 'impregnable'.<sup>37</sup>

Although phrased as a question of 'logical analysis', the scrutiny required by *Bolitho* does not appear confined to 'the avoidance of contradiction and other logical error'.<sup>38</sup> Commentators have argued that this is necessary because a defendant's actions may be simultaneously logical but unreasonable.<sup>39</sup> This, of course, runs both ways and a doctor may well decide to embark on a course of action that does not, *prima facie*, appear logical. This does not, and should not, automatically mean that action undertaken was unreasonable in a legal sense; a lack of logic should not equate to negligence. Commentators have further noted that logic

'is an unusual criterion on which to assess what is, essentially, a matter of clinical judgement and it seems unlikely that the courts will be able to retain control over health care standards if they rely on "logic" alone.'<sup>40</sup>

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<sup>33</sup> Maclean, A., 'Beyond *Bolam* and *Bolitho*' (2002) 5 Med L Internat 205.

<sup>34</sup> Mulheron, above, n 31, p. 610.

<sup>35</sup> Mason, Laurie, above, n 15, p. 153. One example of the reluctance to expand *Bolam* is in respect of patient's best interests: see *Re S* (Sterilisation) [2001] Fam 15.

<sup>36</sup> *Ibid.* See also, for example, *Sutcliffe v BMI Healthcare Ltd* (2007) 98 BMLR 211, CA.

<sup>37</sup> *Ibid.*

<sup>38</sup> Pattinson, S.D., *Medical Law & Ethics*, 3<sup>rd</sup> ed. (Sweet & Maxwell: London, 2011), p. 81.

<sup>39</sup> Teff, H., 'The Standard of Care in Medical Negligence – Moving from *Bolam*?' (1998) 18(3) *Oxford Journal of Legal Studies* 473, p. 481. Also, Jones, M., above, n 27, pp. 238-239.

<sup>40</sup> Mason, Laurie, above, n 15, p. 139.

The difficulty of a pure logic approach was highlighted in *Wisniewski v Central Manchester Health Authority*, wherein Brooke LJ said:

‘It is quite impossible for a court to hold that the views sincerely held by doctors of such eminence cannot logically be supported at all ... and the views of the defendants’ witnesses were views which could be logically expressed and held by responsible doctors.’<sup>41</sup>

If an opinion presented to the court is cogent and well reasoned, it is difficult to argue that it does not withstand logical analysis. *Bolam* provides a good example of this paradox. Here a body of medical opinion supported the approach of the doctor who did not use relaxant drugs during electroconvulsive therapy. The basis of this opinion was that the drugs represented a risk to the patient’s health and it is difficult to argue that such is not cogent and logical. It may not be *reasonable* if the comparative risks of applying the relaxant are outweighed by the risks of undertaking therapy without it, but it could not be said that the opinion did not withstand logical analysis. The nondisclosure of genetic risks give rise to the same problem – from one perspective, it is not reasonable to withhold information that may benefit the health of non-patients (i.e. by enabling access to preventative treatments), but to do so on the basis of protecting confidentiality and, by extension, the doctor-patient relationship is a cogent and logical position to adopt. This would preclude a finding of a breach of duty because the claimant could not demonstrate the opinion failed to withstand logical analysis. Thus *Bolitho* cannot rely on an analysis of logic alone if it is to address the difficulties of *Bolam* in the context of genetics.

The Court of Appeal alluded to this being the case in *Carter v Ministry of Justice*,<sup>42</sup> wherein it was said that professional opinion could be rejected if it did not ‘withstand logical analysis and is thus unreasonable’,<sup>43</sup> indicating that the qualification in *Bolitho* is concerned with ascertaining whether an opinion is both logical *and* reasonable, although Pattinson and Mulheron note that an analysis of the case law using reasonableness is not without its own difficulties.<sup>44</sup> The case of *Marriott v West Midlands Regional Health Authority*<sup>45</sup> also implies that the criteria in *Bolitho* has been interpreted as a question of

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<sup>41</sup> [1998] Lloyd’s Rep Med 223, CA, at 237.

<sup>42</sup> [2010] EWCA Civ 94.

<sup>43</sup> *Ibid.*, at 22.

<sup>44</sup> Pattinson, above, n 38, p. 81. Mulheron, above, n 31, p. 619.

<sup>45</sup> [1999] Lloyd’s Rep Med 23.



reasonableness rather than logic but ‘the situation is still not clear as ... it retained the language of “logic”.’<sup>46</sup> The decision in *Jones v Conwy and Denbighshire NHS Trust*,<sup>47</sup> however, suggests that the distinction between logic and reasonableness has been collapsed and it was held that a delay in ordering a CT scan was neither illogical nor unreasonable. It is therefore unclear what the actual focus of the *Bolitho* qualification is and establishing the appropriate focus of the scrutiny is important in respect of nondisclosure if the shortcomings of the *Bolam* test are to be addressed.<sup>48</sup> In *Bolitho*, Lord Browne-Wilkinson stated:

‘the judge, before accepting a body of opinion as being responsible ... will need to be satisfied that, in forming their views, the experts have directed their minds to the question of comparative risks and benefits and have reached a defensible conclusion on the matter.’<sup>49</sup>

It is therefore implicit in *Bolitho* that for a body of medical opinion to withstand logical analysis, the body, in forming its opinion, must be seen to have adequately weighed the risks and benefits attributable to the contested course of action. This is illustrated by the outcome in *Penney v East Kent Health Authority*,<sup>50</sup> wherein the claimants developed cervical cancer after receiving negative results from screening. The issue was whether or not abnormalities present in the claimants’ slides should have been reported. The defendants argued that the abnormalities were open to interpretation and their experts were of the opinion that the results could be reported as negative. The trial judge, however, held that the *Bolam* test did not apply because no screener acting with reasonable care could have been certain that the abnormalities were not pre-cancerous – a finding with which the Court of Appeal agreed. In addition, Pepitt J stated that had *Bolam* applied to the circumstances, the claimants would have succeeded because the defendants’ opinions were not logical. The ‘experts’ did not possess the ability to distinguish between pre-cancerous and benign cells. Accordingly it can be inferred that the body of opinion would have been

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<sup>46</sup> Mason, Laurie, above, n 15, p. 141.

<sup>47</sup> [2008] EWHC 3172.

<sup>48</sup> Mulheron, above, n 31, identifies seven different categories of scenario in which *Bolitho* has been applied.

<sup>49</sup> *Bolitho*, above, n 24, at 242.

<sup>50</sup> (2000) 55 BMLR 63.

held to have insufficiently weighed the risks and benefits of the course of action adopted. There is clearly very little benefit in reporting a negative result before abnormalities have been properly assessed, while the risk of abnormalities being pre-cancerous is self-evident.<sup>51</sup>

In the context of genetic information it can similarly be argued that not disclosing deleterious genetic traits for which treatment is available amounts to insufficiently weighing the risks and benefits involved in the circumstances. While there is a distinction between reporting a definite negative when a smear test is inconclusive and disclosing genetic information when relatives may share the proband's deleterious trait, the risks and benefits are somewhat analogous. In both scenarios there is a risk that individuals will not be able to seek swift or preemptive intervention because they are unaware of the facts of their situation. As has been highlighted throughout this work, if genetic information is disclosed then the proband's blood relations can seek screening and preventative therapies that would otherwise not be available to them. In *Penney*, knowing that pre-cancerous cells were present in the smear test would have facilitated comparable access to screening and treatment.

A further illustration of the weighting of risks and benefits is provided by *Marriott v West Midlands Health Authority*.<sup>52</sup> Here the claimant suffered a head injury and was rendered unconscious for approximately half an hour. He was taken to hospital but discharged. However, the following week he was lethargic, suffered headaches and a loss of appetite. The claimant was examined by a GP who concluded there was nothing amiss yet four days later his condition deteriorated and he lost consciousness. It was thereafter discovered that he had a hematoma but, despite surgery to remove it, the claimant was rendered permanently disabled. At first instance the judge held that, while the courts should be reluctant to depart from an 'apparently careful and prudent' opinion, the decision not to refer a patient who had suffered head injury

'where he continues to complain of headaches, drowsiness etc., and where there continues to be a risk of the existence of an intracranial lesion which could cause a sudden and disastrous collapse, is not reasonably prudent.'<sup>53</sup>

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<sup>51</sup> See also *Lillywhite v University College London Hospital NHS Trust* [2006] Lloyd's Rep Med 268, which concerned radiological misdiagnosis; *Manning v King's College Hospital NHS Trust* [2009] 110 BMLR 175, wherein a doubtful malignancy was reported as a negative.

<sup>52</sup> (1998) WL 1042499

<sup>53</sup> *Ibid.*

The Court of Appeal affirmed the trial judge's conclusion, Beldem LJ stating that 'it could not be a reasonable exercise of a general practitioner's discretion to leave a patient at home and not refer him back to hospital.'<sup>54</sup> The risk of a blood clot in the circumstances was statistically low but the consequences were dire should that small risk eventuate. It is implied by the courts' judgment that the defendant had not adequately weighed the risks and benefits of referring the patient back to hospital given his symptoms.

The decision in *Marriot* – while indicative that the courts will reject medical opinion where the need arises – was based upon what can be fairly termed as a nonsensical decision. The risk of head injury in the circumstances and the symptoms the claimant was manifesting necessitated further investigation and failure to do so was illogical and irresponsible. Thus *Marriot* does not provide clarification in respect of the disclosure of genetic information and since *Penney* was not decided on this point – Pepitt J's comments being *obiter* – it is persuasive not authoritative. The question therefore is how the analysis of risks and benefits may apply in circumstances concerning the disclosure of genetic risks to the proband's blood relations.

Certainly a body of opinion cannot be described as failing to withstand logical analysis if the risks of disclosure outweigh any potential benefits. Thus a failure to disclose genetic markers indicating incurable diseases – such as Huntington's disease, which may provoke powerful, negative reactions from individuals<sup>55</sup> – could not amount to a breach of duty. Furthermore, any argument that disclosure could be made to engender preparedness is moot because, as Laurie explains, while the

'availability of a cure carries with it the certainty that disclosure can incontrovertibly avert harm ... if disclosure is made to avoid an ancillary harm such as psychological upset there is less of a guarantee that the harm in question will, de facto, be avoided.'<sup>56</sup>

The disclosure of genetic information carries an inherent risk of psychological upset to the recipient, as discussed in preceding chapters. Where there is no therapeutic response

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<sup>54</sup> *Ibid.*

<sup>55</sup> See, for example, Almqvist, E., *et al*, 'A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalisation after predictive testing for Huntington's disease' (1999) 64 *American Journal of Human Genetics* 1293.

<sup>56</sup> Laure, G.T., *Genetic Privacy: a challenge to medico-legal norms* (Cambridge University Press: Cambridge, 2002), p. 122.

available to patients with a particular condition then few, if any, benefits exist justifying disclosing of the deleterious genetic trait. Where disclosure poses a serious psychological risk to the recipient – for example, promotion of suicidal tendencies – therapeutic privilege would also excuse a clinician from making a disclosure. The basis of invoking the therapeutic privilege is so doctors can do what is beneficial for the patients and avoid harming them, which is a possible outcome of disclosing untreatable genetic risks. If the disclosure of certain information is perceived as harmful to their patient, a doctor may be justified in withholding the information under ethical principles of beneficence and non-maleficence. A body of opinion advocating the withholding of information where it is likely to harm cannot be characterised as incapable of withstanding logical analysis, thus there would be no breach of duty for failing to disclose untreatable risks.

However, *Penney* and *Marriott* suggest that when medical opinion has overlooked a particularly important benefit or significant risk (either statistically or in terms of potential harm should it eventuate) then the opinion may fail to withstand logical analysis and the clinician's duty will have been breached. Thus where treatment is available for a genetic condition, it may be open to the courts to hold nondisclosure as illogical because the risks of not disclosing outweighed the risks of breaching confidentiality. The difficulty in reaching such a conclusion is that an opinion in favour of nondisclosure for reasons of confidentiality remains cogent and logical: confidentiality is a cornerstone of medical practice and necessary to preserve the trust between doctor and patient that facilitates effective treatment.

Respect for clinical discretion can also complicate scrutiny of the logic of a body of medical opinion because it may be argued that 'the fact that distinguished experts in the field are of a particular opinion will demonstrate the reasonableness of that opinion'.<sup>57</sup> The problem with this point of view is that it conflates the questions of reasonableness with credibility and raises the hurdle claimants must overcome. Arguably, it becomes increasingly difficult to demonstrate an opinion cannot withstand logical analysis if it is considered reasonable because defendant's expert is perceived as a credible authority.<sup>58</sup> In *Burne v A*,<sup>59</sup> the Court of Appeal did accept that a judge could reject an opinion on what was a responsible course of action providing that the experts delivering that opinion were given the opportunity to justify the practice. However, in *Wisniewski v Central*

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<sup>57</sup> *Bolitho*, above, n 24, *per* Lord Browne-Wilkinson at 243.

<sup>58</sup> See Teff, above, n 17, and Jones, above, n 27, for further analysis about the question of reasonableness becoming lost in credibility.

<sup>59</sup> [2006] EWCA Civ. 24.

*Manchester HA*,<sup>60</sup> the Court of Appeal – despite finding for the claimant – took the opportunity to reaffirm that a body of opinion could only be rejected in rare circumstances.<sup>61</sup> Brooke LJ explained that it was ‘quite impossible for a court to hold that the views sincerely held by doctors of such eminence cannot logically supported at all.’<sup>62</sup> The implication of Brooke LJ’s statement is that the courts should continue to show deference to the medical profession in matters of clinical judgment, which again highlights the paternalism of *Bolam* and the problem of logic as a criterion for assessing breach. *Burne* is consistent with this position because, arguably, it becomes increasingly difficult to dismiss an opinion as incapable of withstanding logical analysis if experts must be given sufficient opportunity to explain and justify a contested practice, particularly if questions of credibility and reasonableness are conflated.

Thus the question is how the courts will judge an opinion supporting nondisclosure where a therapeutic response is available for the identified genetic condition. Adopting a ‘risks versus benefits’ analysis, a body of opinion may be rejected for failing to weight such properly. For example, if the proband is predisposed to bowel cancer and the risk of developing the cancer can be reduced by a daily dose of aspirin, then there is arguably a clear benefit to informing members of the proband’s immediate family who may also be at risk.<sup>63</sup> A body of medical opinion supporting nondisclosure in such circumstances might be rejected on the basis that it does not withstand logical analysis but there is no certainty here. A lot would depend on the comparative risks and benefits of disclosure and nondisclosure; for example, if a body of opinion were to argue that the risk of psychological upset prohibits disclosure of deleterious genetic traits, the risks and benefits may be presented as being insufficiently weighted because the possibility of psychological upset is offset by the availability of treatment. However, an opinion supporting nondisclosure for reasons of doctor-patient confidentiality cannot be easily dismissed, although the logic of the opinion may turn on the level of disclosure required. If, for example, it is unnecessary to identify the patient, then the breach of confidentiality is arguably less intrusive and poses fewer risks than the presence of undiagnosed genetic

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<sup>60</sup> [1998] Lloyd’s Rep Med 223, CA. Herein abnormalities in the foetal heartbeat were not investigated leading to the child suffering brain damage through hypoxia during delivery.

<sup>61</sup> Although whether ‘rare’ is an appropriate descriptor is debatable: see Mulheron, above, n 31.

<sup>62</sup> *Wisniewski*, above, n 60, at 237.

<sup>63</sup> Leifers, G.J., *et al*, ‘Use of Aspirin post-diagnosis improves survival for colon cancer patients’ (2012) 106 British Journal of Cancer 1564.

diseases. Furthermore, the fact disclosure is supported by a public interest may weigh in the claimant's favour.<sup>64</sup>

An alternate justification for nondisclosure might be that healthcare professionals do not believe sufficient benefit is derived from the treatment (for example, a daily dose of aspirin in the case of bowel cancer), or have reservations concerning the side effects of the available treatment. In these circumstances, would the courts consider the comparative risks and benefits to have been incorrectly weighted? Since the courts are unwilling to express a preference where two bodies of medical opinion conflict, deference to medical discretion may operate to deny a breach in the circumstances. If, however, the disorder in question were breast cancer and the treatment option was a double mastectomy then arguments relating to a lack of benefit may be presented as illogical, although arguments regarding doctor-patient confidentiality would remain.<sup>65</sup>

Viewed objectively, the scrutiny of risks and benefits associated with the contested practice is an apparently sensible approach to the question of breach. However, as Heywood cautions, for it to function adequately 'the courts have to be prepared to engage carefully in this assessment in order that it retains any meaningful content', further highlighting that 'the rhetoric of *Bolitho* does not match the outcome [of the case].'<sup>66</sup> Jones also observes that the question of logical analysis can be somewhat hollow, since

'notwithstanding the very clear statements of principle in *Bolitho*, there is no evidence that their Lordships undertook an analysis of the balance of risk nor is it apparent why the balance came down against the plaintiff's claim'.<sup>67</sup>

Although there is evidence to suggest that the courts have subsequently engaged in an analysis of the risks and benefits associated with contested medical practices, scrutiny of expert opinion continues to remain exceptional. Thus there is no certainty that a body of opinion supporting the nondisclosure of genetic risks when treatment is available will be held as failing to withstand logical analysis. If, however, the question of disclosing genetic information is perceived as accessible to the lay person – meaning that, in the eyes of the court, it lacks the technicality and complexity attributed to other medical procedures – then

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<sup>64</sup> See chapter two.

<sup>65</sup> For example, see 'Rackheath woman's tough decision to have her breasts removed after her mum died from cancer', *Norwich Evening News*, 23<sup>rd</sup> October 2012.

<sup>66</sup> Heywood, above, n 26, p. 228.

<sup>67</sup> Jones, above, n 27, p. 247.

the judiciary may be more willing to engage in an analysis of expert opinion. Thus if there existed a clear precaution against an adverse outcome that was ‘obvious as a matter of lay common sense’ then the doctor’s conduct may be negligent even though a responsible body endorsed it.<sup>68</sup> This possibility has been recognised by the judiciary. In *French v Thames Valley Strategic Health Authority*,<sup>69</sup> Beatson J noted

‘it is more likely that the courts will find a practice unreasonable where a case does not involve difficult or uncertain questions of medical treatment or complex, scientific or highly technical matters, but turns on failure to take a simple precaution, the need for which is obvious to the ordinary person considering the matter’.<sup>70</sup>

In the pre-*Bolitho* case of *Hucks v Cole*,<sup>71</sup> a doctor prescribed a five-day course of medication to a new mother complaining of sores and yellow spots on her fingers and toes. The doctor ceased treatment once there was visible improvement despite the fact that the sores contained an infection capable of causing puerperal fever, which the claimant then developed. The doctor’s alleged breach was in failing to dispense penicillin, which would have treated the infection and prevented the subsequent fever. A body of medical opinion supported the doctor’s conduct, but Sachs LJ in the Court of Appeal did not consider every precaution to have been taken given advances in medical science at the time. He rejected the body of opinion because it demonstrated ‘a residual adherence to out-of-date ideas’ that ‘on examination do not really stand up to analysis’.<sup>72</sup> Since penicillin would have treated the initial infection and prevented puerperal fever, prescribing it to the patient constituted a precaution ‘obvious as a matter of lay common sense’.<sup>73</sup>

The critical issue is whether a particular decision is considered accessible to the layperson; when it is, the courts are more willing to subject a decision to scrutiny. Recent examples of finding a clear precaution not being taken include failing to consult with more experienced specialists about a patient’s condition;<sup>74</sup> failing to ask a series of leading

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<sup>68</sup> Mulheron, above, n 31, p. 620.

<sup>69</sup> [2005] EWHC 459.

<sup>70</sup> *Ibid.*, at 112.

<sup>71</sup> [1993] 4 Med LR 393. The actual decision was handed down in 1968.

<sup>72</sup> *Ibid.*, at 399.

<sup>73</sup> Mulheron, above, n 31, p. 621.

questions (via telephone) to a mother whose child was ill;<sup>75</sup> failing to maintain ‘good lines of communication’ between hospital and cytogenetic laboratory regarding genetic testing of a sample;<sup>76</sup> and failing to assign a negative status to slides where the ‘absolute confidence’ threshold could be met.<sup>77</sup> In *Lowe v Haverling Hospitals NHS Trust*,<sup>78</sup> the clear precaution the defendant failed to take ‘was as simple as a more rigorously arranged series of medical appointments for the patient’.<sup>79</sup> Where there is uncertainty or a decision is technically complex or experts disagree regarding the risks involved in a precaution, the courts are less willing to subject the conduct in question to scrutiny. Thus in *Macey v Warwickshire HA* there was no breach in respect of a failure to intubate a baby experiencing respiratory difficulties; although opinion differed regarding the risks of intubation, both opinions were considered logical and rational.<sup>80</sup> Likewise, in *French*, differing opinions were put forward in respect of the handling of preeclampsia. The area was complex and technical and thus was not considered accessible to the layperson.

The decision to disclose genetic risks (or not to disclose them, as may be the case) when a therapeutic response is available may be a practice that is accessible to the layperson. Warning the proband’s blood relations of a deleterious genetic trait – and thus facilitating access to screening and treatment – can certainly be characterised as a precaution that is ‘obvious as a matter of lay common sense’. Alternately, it could be portrayed as an area of mild technicality, but disclosure concerns dissemination of information as opposed to technically complex matters of treatment. In *French*, Beaston J highlighted the disclosing of risks involved in a proposed treatment as being an area accessible to the ordinary person, thus it can be implied that disclosure of genetic risks is likewise accessible. It is possible that the courts will be more willing to subject decisions concerning disclosure to scrutiny. However, given the judiciary’s longstanding deference to the medical profession when it comes to standards of care, and the fact that it can be argued as ‘quite impossible for a court to hold that the views sincerely held by doctors ...

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<sup>74</sup> *Gascoigne v Sheridan & Co.* [1994] 5 Med LR 437.

<sup>75</sup> *Burne*, above, n 59.

<sup>76</sup> *Farraj v Kings College Healthcare NHS Trust* [2008] EWHC 2468 (QB).

<sup>77</sup> *Penney*, above, n 50.

<sup>78</sup> (2001) 62 BMLR 69.

<sup>79</sup> *Mulheron*, above, n 31, p. 622.

<sup>80</sup> [2004] EWHC 1198 (QB).



cannot logically supported at all',<sup>81</sup> opinions supporting the nondisclosure of genetic risks may not be sufficiently scrutinised or – in the event they are – may not be rejected as failing to withstand logical analysis. While *Bolitho* offers an opportunity to address the shortcomings of *Bolam* in the genetic context and hold that nondisclosure is a breach of duty, there is no guarantee that the courts will subject medical decision making to sufficient scrutiny.

### *Information Disclosure Cases*

The shortcomings of *Bolam* and the apparent reluctance of the courts to hold a body of medical opinion as not withstanding logical analysis indicates an alternate approach to breach may be necessary, otherwise a duty to disclose may end up being a hollow obligation. Discretion is an essential element of medical practice but in the context of the proposed duty being able to justify nondisclosure when treatment is available defeats the purpose for which the duty is conceived.

A useful steer emerges from doctor's duty of care to their patients, which incorporates an obligation to make sufficient disclosure of risks inherent in any proposed treatment. In this context the courts' assessment of breach has departed from the traditional *Bolam* perspective and has started establishing a standard of care by reference to what the reasonable person would have wanted to know in the circumstances. This approach, imperfect though it is, avoids the problems created by the deference shown to medical professionals in *Bolam* and *Bolitho*. Given it is already applied in the context of disclosure – although within the doctor-patient relationship – it may be a suitable alternative to *Bolam* when assessing breach of duty. The crucial question is how to assess what the reasonable person would want to know in respect of genetic risks.

It is important to note at this juncture that the underlying argument in doctor-patient disclosure cases is consent, as the claimant is arguing that had they been informed of the risk, they would not have consented to the respective treatment. Because the tort of negligence does not recognise 'a patient's inherent interest in material information ... informed consent becomes a route for patients to seek financial compensation.'<sup>82</sup> Because the underlying issue here is consent, claims arising from nondisclosure within the doctor-patient relationship are distinguishable from claims involving the nondisclosure of genetic information, which are concerned with an eventuation of a risk of disease. The two types of claim are, however, analogous in that both are concerned with the withholding of

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<sup>81</sup> Wisniewski, above, n 60, at 237.

<sup>82</sup> Jackson, E., *Medical Law: Texts, Cases and Materials*, 3<sup>rd</sup> ed. (OUP: Oxford, 2013), p. 300.

information that, had a disclosure been made, may have informed and influenced the conduct of the claimant. In cases of doctor-patient nondisclosure, the information would have affected the patient's consent to the proposed therapy; in cases of genetic nondisclosure, knowledge of the risks enables blood relations to seek preventative therapies or preemptive treatment.

Application of *Bolam* to questions of nondisclosure within the doctor-patient relationship has produced unsatisfactory results and underscores the shortcomings of the test in respect of claims concerning genetic information. As previously explained, *Bolam* is inherently paternalistic. In the context of disclosure, this can perpetuate a doctor-knows-best approach to the question 'what should be disclosed?' and *Bolam* itself provides the perfect illustration. Herein McNair J directed the jury that the appropriate question was whether the defendant's actions had fallen 'below a proper standard of competent professional opinion on ... whether or not it was right to warn.'<sup>83</sup> The emphasis was on what the responsible body of medical opinion would or would not have disclosed and in the context of genetic information this means nondisclosure, despite the existence of treatment, may be justifiable providing a responsible body of medical opinion concurs with such conduct. McNair J also explained that the jury was entitled to conclude that when a doctor

'has a strong belief that his [the patient's] only hope of cure is submission to electroconvulsive therapy, the doctor cannot be criticised if he does not stress the dangers, which he believed to be minimal, involved in that treatment.'<sup>84</sup>

The content of doctor-patient disclosure was therefore originally considered to be the preserve of clinical discretion. Absent a clear consensus on disclosure within the medical profession – and with the courts reluctant to express a preference for one body of medical opinion above another – the doctor occupied the role of arbiter of what information patient's received, which in turn influenced the treatment to which they consented. Two important cases challenged this status quo and these and subsequent cases are informative in respect of how breach should be assessed in claims concerning the nondisclosure of genetic risks. The two key cases are *Sidaway v Board of Governors of the Bethlem Royal Hospital*<sup>85</sup> and *Pearce v Bristol United Healthcare NHS Trust*.<sup>86</sup>

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<sup>83</sup> [1957] 2 All ER 118 at 124.

<sup>84</sup> *Ibid.*

<sup>85</sup> [1985] AC 871.

*Sidaway* concerned a failure to disclose a slight risk of paralysis inherent in spinal surgery that the patient was undergoing. The risk eventuated and the claimant sued alleging that had the risk been disclosed prior to her undergoing the operation she would not have consented to the procedure. *Pearce* concerned the *in utero* death of the claimant's child, which was two weeks overdue when the claimant saw the defendant clinician. The claimant wished to have the birth induced or undergo caesarian section but the doctor advised her that it would be risky to induce birth and her recovery from a caesarian would be lengthy, preferring to allow nature to take its course. The doctor neglected to mention a slight risk of *in utero* death as a result of the delay in delivery. Their Lordships' judgment in *Sidaway* (while not entirely clear) laid the foundations for the approach to breach in information disclosure cases, which was subsequently refined by the Court of Appeal in *Pearce*. Thus in order to understand how the assessment of breach is developing in this context – and how it may then be extrapolated to the nondisclosure of genetic information – it is necessary to consider both judgments.

One of the key points of discussion in *Sidaway* was whether *Bolam* had a role to play in claims regarding medical nondisclosure. In the Court of Appeal, skepticism regarding the role of *Bolam* was aired, with Donaldson MR asserting that the courts could not 'stand idly by if the profession, by an excess of paternalism, denies their patients a real choice.'<sup>87</sup> This observation is also relevant in respect of genetic information because the paternalism of *Bolam* means that nondisclosure may be justified, which has the effect of denying the proband's blood relations access to screening and treatment and emptying a duty to disclose of content. However, despite airing reservations, the court continued to apply *Bolam*, concluding that McNair J's test was 'the primary test of liability for failing to disclose sufficient information'.<sup>88</sup>

In the House of Lords, Lord Scarman was also skeptical about the appropriateness of *Bolam* in nondisclosure claims, stating that he found it 'disturbing' that determination of the scope of the duty of care should be left to the profession.<sup>89</sup> He argued 'the courts should not allow medical opinion as to what is best for the patient to override the patient's right to decide'.<sup>90</sup> Lord Diplock, in contrast, saw no justification for distinguishing

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<sup>86</sup> [1999] PIQR 53.

<sup>87</sup> [1984] QB 493 at 513.

<sup>88</sup> *Ibid.*

<sup>89</sup> *Sidaway*, above, n 85, at 882.

<sup>90</sup> *Ibid.*

between disclosure of risks and diagnosis and treatment and applied the *Bolam* test. Lord Bridge, with whom Lord Keith concurred, argued ‘a decision [about] what degree of disclosure of risks is best ... must primarily be a matter of clinical judgement.’<sup>91</sup> Lord Templemen was of a similar disposition, stating where a doctor conscientiously endeavoured to explain arguments for and against a major operation the court should ‘be slow to conclude that the doctor has been guilty of a breach of duty ... merely because the doctor omits some specific information.’<sup>92</sup>

In the main the *Bolam* test was applied, perpetuating a doctor-knows-best approach to information disclosure and representing a missed opportunity to robustly defend the patient’s right to choose. However, Lord Bridge added an important caveat to the principle that was subsequently picked up and developed by the Court of Appeal in *Pearce*. He accepted that it would not be justifiable to withhold risks from patients in all circumstances – even if a body of medical opinion supported such practice – and explained that while disclosure was primarily a matter of clinical judgement it was open to a court to ‘come to a conclusion that disclosure of a particular risk was so obviously necessary ... that no reasonably prudent medical man would fail to make it.’<sup>93</sup> Lord Templemen agreed that clinical discretion was limited in respect of disclosure, stating that he had ‘no doubt that a doctor ought to draw the attention of a patient to a danger which may be special in kind or magnitude or special to the patient.’<sup>94</sup> But while their Lordships acknowledged that there were limits to clinical discretion in this context, they did not provide these limits the necessary clarity. Lord Bridge referred to ‘a substantial risk of grave adverse consequences’<sup>95</sup> and gave the example of a ten per cent risk of a stroke, but his example raises more questions than it answers. As Jackson explains

‘while we know that Lord Bridge believed a 1-2 per cent risk of spinal cord damage was not a substantial risk of grave adverse consequences, and a 10 per cent risk of a stroke was such a risk, his judgment begs the question how to draw the line

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<sup>91</sup> *Ibid.*, at 900.

<sup>92</sup> *Ibid.*, at 904.

<sup>93</sup> *Ibid.*, at 900.

<sup>94</sup> *Ibid.*, at 903.

<sup>95</sup> *Ibid.*, at 900.

between these to points of certainty. Is a 5 per cent risk of a stroke sufficient; or a 2 per cent risk of death?’<sup>96</sup>

In the context of genetic nondisclosure, *Sidaway* does not provide a sufficient point of reference for the assessment of breach. The relatively opaque example provided leaves unanswered whether a risk of sharing a genetic disorder is a risk of grave adverse consequences consistent with the judgment of Lord Bridge. Is a potentially shared mutation on the BRCA1 or BRCA2 gene sufficient to trigger the caveat his Lordship appeared to be suggesting? Certainly it must be noted that the foci of Lord Bridge’s judgment was ostensibly risks inherent in operations, but this does not mean all risks outside of the operating theatre are not grave enough consequences. The case of *Penney* suggests that a risk of cancer is to be perceived as a substantial risk as the defendant was found liable therein for reporting abnormal results during screening as negative. It can be suggested that a genetic risk of cancer may also represent a significant risk and is therefore likely to be consistent with Lord Bridge’s judgment. Whether a rare condition, or one with a low penetrance,<sup>97</sup> would be considered a substantial risk is less clear.

The difficulty with Lord Bridge’s judgment is, as Kennedy highlights, is that it ‘beg[s] the central question: “substantial” and “grave” to whom?’<sup>98</sup> Thus whether or not the genetic risk of cancer – or any other genetic risk – is substantial depends on the perspective adopted by the courts. If the assessment of what is substantial and grave is conducted from the perspective of the patient, it would be inconsistent with his Lordship’s rhetoric, introducing ‘a subjective patient-orientated standard ... inconsistent with Lord Bridge’s rejection of the less radical objective prudent patient test.’<sup>99</sup> Kennedy suggests that the assessment is made from the perspective of the court,<sup>100</sup> which, in practice, is not dissimilar from the objective standards of the prudent patient test that Lord Bridge ‘dismissed as unworkable’.<sup>101</sup> The perspective adopted when assessing breach is important because it will significantly alter perceptions of risk: a clinician’s view may be sway by statistical significance, whereas the patient may focus upon the spectre of the potential

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<sup>96</sup> Jackson, above, n 82, p. 274.

<sup>97</sup> The likelihood of the condition manifesting.

<sup>98</sup> Kennedy, I., *Treat Me Right* (OUP: Oxford, 1988), pp. 200-201.

<sup>99</sup> Jackson, above, n 82, p. 274.

<sup>100</sup> Kennedy, above, n 98 p. 201.

<sup>101</sup> Jackson, above, n 82, p. 201.

outcome. Thus, depending on the courts' chosen yardstick, the relevant standard of care could vary considerably. In *Rogers v Whitaker*<sup>102</sup> the Australian High Court parted company with a *Bolam* assessment of whether a risk was material and thus should be disclosed and adopted a patient-orientated standard. The claimant lost sight in both eyes as a result of surgery and, even if the operation was performed with due care, a statistically slight risk of blindness existed. The surgeon did not disclose the risk and it was argued this constituted negligence. The court articulated a risk as material if 'a reasonable person in the patient's position ... would be likely to attach significance to it or if the medical practitioner is or should be reasonably aware that the particular patient ... would be likely to attach significance to it.'<sup>103</sup> It is important to note that the test is not entirely subjective: it operates from a baseline of what the reasonable patient would find significant. The second part of the test introduces an assessment of 'whether or not there is anything specific to that patient that would render a risk significant' and thus require disclosure.<sup>104</sup> The critical point in *Rogers* was that the patient had stressed the importance of not losing her sight, thus demonstrating the significance of the undisclosed risk to her.

The *Rogers* standard may be criticised as a radical departure from the objective basis of negligence and a heavy burden upon doctors encouraging excessive risk disclosure.<sup>105</sup> It is true that a subjective standard could lead to healthcare practitioners disclosing more than they previously would have in order to discharge their duty, but the standard would cut both ways. Since patients 'sometimes prefer to proceed in ignorance and research suggests this happens not infrequently',<sup>106</sup> courts would be unlikely to hold a doctor liable where a patient expresses a wish not to know but then recounts *ex post facto*. In principle, a subjective approach could link in with respect for the right not to know. Where a prospective recipient of genetic information expressed a wish not to be informed, nondisclosure could not amount to breach, meaning a more nuanced standard of care could

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<sup>102</sup> (1992) 109 ALR 625.

<sup>103</sup> *Ibid.*, at 634.

<sup>104</sup> Heywood, R., *Subjectivity in Risk Disclosure: considering the position of the particular patient* (2009) 25(1) PN 3, p. 9.

<sup>105</sup> *Ibid.*, pp. 10-11.

<sup>106</sup> *Ibid.*, pp. 11-12. See Timmermans, L., *et al*, 'Monitoring and Blunting in Palliative and Curative Radiotherapy Consultations' (2007) 16 *Psycho-Oncology* 1111; Henwood, F., "'Ignorance is Bliss Sometimes": Constraints on the Emergence of the "Informed Patient" in the Changing Landscapes of Health Information' (2003) 25 *Sociology of Health and Illness* 589; Beresford, N., *et al* 'Risks of Elective Cardiac Surgery: What Do Patients Want to Know?' (2001) 86 *Heart* 626; Gilmore, A., 'Treating the Terminal Patient: "Ignorance is Rife"' (1986) 135 *Canadian Medical Association Journal* 235; Miller, S., 'Coping with Impending Stress: Psychophysiological and Cognitive Correlates of Choice' (1979) 16 *Psychophysiology* 572.

be developed recognising different outlooks on genetic risks. The problem with a subjective standard in the genetic context is the impracticality of ascertaining the views of persons beyond the therapeutic relationship. It is one thing to know a patient may hold a risk significant because, during consultation, they stress they do not want to lose their sight, it is quite another to know what a patient's relatives may view as significant. The burden of obtaining this knowledge is unlikely to be insubstantial. An objective standard, akin to the reasonable patient element of the *Rogers* test, is potentially more practical in the context of genetic risks.

There is some evidence of a reasonable patient standard creeping into domestic law, although the extent to which it influences the question of breach is open to conjecture. In *Pearce* the Court of Appeal favoured the approach of Lord Bridge – Lord Woolf MR stating that ‘the views of the majority [in *Sidaway*] most clearly appear from the speech of Lord Bridge’<sup>107</sup> – whilst distancing itself from the judgment of Lord Templeman.<sup>108</sup> The core issue in *Pearce*, like *Sidaway* before, was whether a doctor breached his duty by failing to disclose certain risks: specifically, the risk of *in utero* death of the patient's child. Considering what should be disclosed to patients, the Court of Appeal held

‘if there is a significant risk which would affect the judgement of a reasonable patient, then in the normal course it is the responsibility of a doctor to inform the patient of that significant risk, if the information is needed so that the patient can determine for him or herself as to what course of action he or she should adopt’.<sup>109</sup>

The language adopted by the Court of Appeal would appear to ‘indicate a more robust commitment to the patient's right to information’,<sup>110</sup> but the outcome of the case did not match the rhetoric. In deciding whether or not the clinician was negligent, Lord Woolf MR highlighted that ‘the doctors called on behalf of the defendants did not regard that risk [*in utero* death] as significant’.<sup>111</sup> This statement indicates that in *Pearce* the definition of a significant risk was drawn from the perspective of medical practitioners and not the patient. Despite consistent assertions to the contrary under cross examination, it was

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<sup>107</sup> *Pearce*, above, n 86, at 57.

<sup>108</sup> *Ibid.*, at 58. It was explained that his approach was not in keeping with the majority although it did ‘reflect the law’.

<sup>109</sup> *Ibid.*, at 59, emphasis added.

<sup>110</sup> Jackson, above, n 82, p. 277.

<sup>111</sup> *Pearce*, above, n 86, at 59.

concluded that had the claimant ‘been able to understand what she had been told about the increased risk, her decision would still have been to follow, reluctantly, the advice of the doctor’.<sup>112</sup> Thus while the court appeared to adopt a reasonable patient standard, adducing significance by reference to the opinion of the medical profession means the judgment and reasoning can be reconciled with the *Bolam* test.<sup>113</sup>

The judgment of Lord Woolf, however, does appear to have laid foundations for a departure from *Bolam* in respect of negligent disclosure. Subsequent cases appear to have adopted this trajectory and it has been suggested that healthcare practitioners must have regard for the perceptions of their patient in respect of risks. In *Wyatt v Curtis*,<sup>114</sup> Sedley LJ suggested Lord Woolf’s formulation refined Lord Bridge’s test by recognising that ‘what is substantial and grave are questions on which the doctor’s and the patient’s perception may differ’ thus doctors must ‘have regard to what may be the patient’s perception.’<sup>115</sup>

In *Chester v Afshar*,<sup>116</sup> the House of Lords did not consider the issue of breach but did approve of Lord Woolf MR’s approach, stating:

‘A surgeon owes a legal duty to a patient to warn him or her in general terms of possible serious risks involved in the procedure ... In modern law medical paternalism no longer rules and a patient has a prima facie right to be informed by a surgeon of a small, but well established risk’.<sup>117</sup>

The courts thus appear to be wriggling away from an assessment of breach based on *Bolam* though the extent to which a reasonable patient test has been adopted is open to debate. In *Pearce*, Lord Woolf MR judged the seriousness of risks from the opinion of the clinicians but cases such as *Wyatt* and *Chester* have placed an emphasis on the reasonable patient’s perception of risk.<sup>118</sup> *Birch v University College London Hospital NHS Foundation*

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<sup>112</sup> *Ibid.*, at 60.

<sup>113</sup> Mason, Laurie, above, n 15, p. 118.

<sup>114</sup> [2003] EWCA Civ. 1779. The case concerned a lack of disclosure of the risk of foetal abnormality resulting from a mother contracting chicken pox during pregnancy.

<sup>115</sup> *Ibid.*, at 16.

<sup>116</sup> [2005] 1 AC 134.

<sup>117</sup> *Ibid.*, at 143.

<sup>118</sup> A question is whether this is actually a more flexible standard than *Bolam*. See Miola, J., ‘On the Materiality of Risk: Paper Tigers and Panaceas’ (2009) 17(1) Med Law Rev 74.



*Trust*<sup>119</sup> – where it was held that failure to disclose an alternative, less risky means of diagnosis constituted a breach of duty – may also indicate that the doctor’s duty of disclosure is assessed by reference to the reasonable patient as opposed to *Bolam*. However, in *Montgomery v Lanarkshire Health Board*,<sup>120</sup> both houses of the Court of Session applied *Sidaway* and *Bolam* to the issue of disclosure, rejecting the claimant’s argument that *Pearce* extended the duty to significant risks that would affect the judgment of a reasonable patient. The case concerns an alleged mismanagement of a diabetic mother’s labour; delivery was complicated by shoulder dystocia and, as a result, the baby was deprived of oxygen. Subsequently the infant was diagnosed with cerebral palsy. The Outer House held ‘it is to the risk of adverse outcome to which the court should have regard when considering whether a warning should be given’,<sup>121</sup> concluding the risks of shoulder dystocia were ‘far short of amounting to a substantial risk of grave consequences’.<sup>122</sup> The Inner House affirmed this finding, explaining ‘what is of interest to the patient must be the outcome, adverse or otherwise, and not some possible complication’.<sup>123</sup> The chances of shoulder dystocia occurring during the labour of diabetic women are nine to ten per cent, which is not insignificant, thus the insubstantial nature of the risk appears to have been deduced from the fact that in the vast majority of cases it is ‘successfully addressed, without incident, by well recognised ordinary midwifery procedures; and in many cases the mother would not be aware of any problem having arisen.’<sup>124</sup> The case has been appealed to the Supreme Court, with judgment expected in early 2015, thus any perceived move towards a reasonable patient standard must presently be regarded with caution.

Furthermore, the lack of reference to *Bolam* – particularly by the House of Lords in *Chester* – does not necessarily preclude clinicians from avoiding liability because nondisclosure is consistent with a responsible body of medical opinion. As Herring notes, the assumption appears to be ‘that no responsible body of medical opinion would think it

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<sup>119</sup> (2008) 104 BMLR 168.

<sup>120</sup> [2010] CSOH 104; [2013] CSIH 3.

<sup>121</sup> [2010] CSOH 104, at 233.

<sup>122</sup> *Ibid.*, at 234.

<sup>123</sup> [2013] CSIH 3, at 29.

<sup>124</sup> *Ibid.*

inappropriate to disclose a serious risk to patients.’<sup>125</sup> Thus while there is evidence suggesting claims concerning negligent disclosure were departing from *Bolam*, the waters are presently muddled. If the Supreme Court affirms a reasonable patient standard in *Montgomery*, an argument could be made for breach in the genetic context to be assessed from the perspective of the reasonable blood relation. This is because considering breach from either the perspective of healthcare practitioners or the proband may lead to a clash of rhetoric comparable to *Pearce*. The proband and clinicians do not occupy the position of family members – they do not necessarily share their perspective on significant risks. Although it could be argued that by submitting for genetic testing the proband clearly believes the potential risk is significant, thus (by extension) it should be disclosed to blood relations. Certainly it could be posited that the reasonable relation would want to know what the proband finds significant, but the proband might not necessarily submit to testing for treatable conditions or do so for reproductive reasons. Using the proband’s perception of significant as a barometer might cast the net too wide. If the proband’s perspective is rejected, the question this leads to is what will the reasonable blood relation want to know in respect of genetic risks?

Establishing what constitutes a risk that must be disclosed is one problem that may arise. In *Sidaway*, *Pearce* and *Chester* the labels ‘serious’ or ‘significant’ are applied to the type of risks that it would be negligent not to disclose. The question then is to what ‘serious’ or ‘significant’ refer. Is it the statistical chance of a risk eventuating or the spectre of the outcome should the risk manifest? The case law concerning doctor-patient disclosure is inconsistent on this point: *Pearce* and *Sidaway* focus on the statistical possibility of a risk eventuating, whereas *Chester* and *Birch* appear to link seriousness with the potential outcome. This is illustrated by the fact that the claimants recovered for statistically low but serious risks in the latter cases but the claims failed in the former.

The difficulty with respect to genetic risks is if the courts are concerned with the statistics, the statistical likelihood of a disorder eventuating may become a determining factor in deciding whether it constitutes a serious enough risk to warrant disclosure. Thus individuals with a genetic predisposition of low penetrance may not be informed of the risk of developing a serious but treatable disorder, whereas an individual whose genome indicates a highly penetrant risk of a treatable disease would be informed of that risk. Reliance on statistics would likely result in an inconsistent application of a duty to disclose, which is undesirable. If both risks of disease are treatable then nondisclosure denies blood relations access to medical intervention in both instances, but if the

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<sup>125</sup> Herring, J., *Medical Law & Ethics*, 5<sup>th</sup> ed. (OUP: Oxford, 2014), p. 166.

seriousness of a risk – and thus whether nondisclosure is a breach of duty – is determined by statistics, those whose deleterious genetic traits are less likely to manifest will be left without redress where the condition eventuates, much like the claimants in *Sidaway* and *Pearce*. Alternately, if seriousness and the need to disclose were determined by reference to the spectre of the outcome – say breast or ovarian cancer – then inconsistency created by using statistics as a crutch is avoided and an arguably unsustainable line between conditions of comparable seriousness but varying penetrance is avoided.

A useful starting point in determining what risks the reasonable relation would wish disclosed is provided by the American College of Medical Genetics and Genomics (ACMG). In its high profile 2013 recommendations on the reporting of incidental findings in gene sequencing,<sup>126</sup> the ACMG identified a ‘minimum list’ of incidental findings that should routinely be disclosed.<sup>127</sup> The minimum list prioritised ‘disorders for which *preventive measures and/or treatments were available* and disorders in which individuals with pathogenic mutations might be asymptomatic for long periods of time’,<sup>128</sup> the focus on preventative measures or treatment linking neatly to the proposed scope of a duty to disclose genetic risks. The ACMG’s recommendations are concerned with what *incidental* genetic risks should be disclosed to the proband but it provides a starting point for mapping out what information should be disclosed to blood relations and when failure to do so would constitute a breach of duty.

Assessing the seriousness or significance of genetic risks by outcome and not statistics is an apt approach to defining what the reasonable relation would want to be apprised of. It would create a presumption that claimants would want to know about serious, treatable risks and failure to disclose such would amount to a breach of the doctor’s duty. The obvious objection is that the presumption would disregard blood relations’ interest in not knowing, a problem encountered in respect of the proband by the ACMG and which has seen the recommendations amended to allow for patients to opt out of receiving incidental genetic information during the early phases of the screening process.<sup>129</sup> The problem is that blood relations are not able to opt out because they are not

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<sup>126</sup> American College of Medical Genetics and Genomics, ‘ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing’ (2013) 15(7) *Genet Med* 565.

<sup>127</sup> Incidental findings are ‘the results of a deliberate search for pathogenic or likely pathogenic alterations in genes that are not apparently relevant to a diagnostic indication for which the sequencing test was ordered.’ *Ibid.*, p. 566.

<sup>128</sup> *Ibid.*, p. 567.

<sup>129</sup> American College of Medical Genetics and Genomics, ‘ACMG Updates Recommendations on “opt out” for Genome Sequencing Return of Results’ (ACMG, Bethesda: 2014).

party to the screening process to the extent the proband is. A compromise position must therefore be sought which balances the doctor's duty to disclose with relatives' potential interest in not knowing. Disclosure would therefore need to be conducted carefully. An appropriate approach may be distilled from research conducted in Australia in 2006. Family members did not consider it a breach of privacy nor autonomy to receive a letter disclosing that they may be genetically at risk of cancer, even when respondents declined to receive any further information.<sup>130</sup> The letter was worded in general terms and did not identify the proband or the familial cancer syndrome, mutation, or details of cancer risk. Thus highlighting the possibility of a shared risk in a family unit does not necessarily prevent exercise of the right not to know because individuals remain able to decide for themselves whether or not to pursue screening. In this way, the right not to know would be preserved insofar as practicable because, while a risk is identified, choosing whether or not to find out more through genetic sequencing remains a decision for the individual.

### *Conclusion*

If a duty to disclose is established then the assessment of breach must not empty the duty of content, otherwise it becomes a superfluous legal obligation. The traditional approach to breach in cases of medical negligence, the *Bolam* test, poses difficulties because it incorporates a necessary respect for clinical discretion, with the determining of the appropriate standard of care drawing upon responsible bodies of medical opinion. The problem that arises in respect of genetic risks is that both disclosure and nondisclosure are potentially justifiable under *Bolam*, as the courts are reluctant to choose between bodies of medical opinion. Thus a failure to disclose a treatable risk may not necessarily constitute a breach of duty. This problem may be overcome if the courts engage with the criteria in *Bolitho* and assess whether medical conduct withstands logical analysis. However, it is difficult to prove that medical opinion is illogical and it is not certain that the courts meaningfully engage with this exercise, thus *Bolitho* may not sufficiently bridge the difficulties of the *Bolam* approach to breach.

Another option in respect of assessing breach may be found in cases concerning the nondisclosure of risks to patients, wherein the courts appear to have departed from a *Bolam* approach and started to assess breach by reference to what the reasonable patient would have wanted to know in the circumstances. The language used in these cases has referred

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<sup>130</sup> Suthers, G.K., *et al*, 'Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder' (2006) 43 *J Med Genet* 665. Of 351 family members contacted, 25 respondents indicated a wish not to receive any further information.

to serious or significant risk and whether this is determined by statistics or by reference to the seriousness of the outcome should the risk eventuate. It has been suggested here that the courts are beginning to adopt the latter definition of a serious risk and thus serious, yet treatable genetic conditions may be categorised as significant enough to warrant disclosure to the proband's blood relations. Although there may be some conflict with a right not know, adopting the approach to breach used in cases of doctor-patient disclosure may prevent the duty to disclose being rendered hollow because nondisclosure is supported by a responsible body of medical opinion. However, a note of caution is necessary in respect of arguments based on a reasonable patient standard because the forthcoming Supreme Court decision in *Montgomery* may restate *Sidaway* as the leading authority and reaffirm *Bolam* as the appropriate standard of disclosure.

## 7. CAUSATION

### *Issues with Causation*

The third requirement of any negligence action is proof of a causal link between the harm the claimant has suffered and the negligence committed by the defendant. If a duty to disclose is held to exist between the proband's doctor and their blood relations and nondisclosure is accepted as amounting to a breach of duty – either using a traditional *Bolam* approach or through an alternate test derived from litigation concerning doctor-patient disclosure – then any claim will stand or fall on whether the claimant can demonstrate a sufficient causal link between nondisclosure and the harm suffered. Without such a link, the claimant's action will ultimately fail regardless of whether or not the defendant has actually behaved negligently.<sup>1</sup> Therefore causation is a crucial element in crafting a duty to disclose because the duty may be emptied of content if a causal link, and thus liability, cannot be established.

Where a claim in negligence involves an act of physical interference – an obvious example being injury caused by negligent driving – causation is not a complex conundrum. If the claimant is struck by the defendant's car, the impact breaking their leg, the causal link between negligence and harm is straightforward to establish. As Chico has written, negligence is at its happiest when dealing with knotty problems of a psychical nature and this is particularly true of causation.<sup>2</sup> The problem for claimants in medical negligence cases is that 'there will usually be at least two possible causes of the patient's injury: the doctor's actions and the patient's pre-existing condition.'<sup>3</sup> This observation is pertinent to genetic information and risks because the cause of injury can be portrayed as either the individual's genetic predisposition to the eventuating condition or the clinician's failure to disclose the risk.

The key causation question in respect of genetic information is how the causal link is to be satisfied given that at least two possible causes for any injury will be present. The traditional approach to causation in English tort law is the 'but for' test, which necessitates the claimant 'prove that the tort has probably caused the injury or condition suffered.'<sup>4</sup> In the example of negligent driving, this is a relatively straightforward proposition but

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<sup>1</sup> See, for example, *Barnett v Chelsea & Kensington hospital Management Committee*, *Hotson v East Berkshire AHA*, *Bolitho v City & Hackney Health Authority*

<sup>2</sup> Chico, V., *Genomic Negligence: an interest in autonomy as the basis for novel negligence claims generated by genetic technology* (Routledge-Cavendish, Abingdon: 2011), p. 16.

<sup>3</sup> Jackson, E., *Medical Law: Texts, Cases and Materials*, 3<sup>rd</sup> ed. (OUP: Oxford, 2013), p. 140.

<sup>4</sup> *Sienkiewicz v Greif (UK) Ltd* [2010] QB 370 at 371-372.

difficulties arise when more than one causal agent exists. The balance of probabilities – the evidential burden upon which causation is measured – is subjected to scrutiny where two potential causal agents exist and the onus is ‘on the claimant to prove on a balance of probabilities which of them has caused the damage’;<sup>5</sup> in plain terms, this means that it must be established that the defendant’s negligence more likely than not caused the injury. In statistical terms, the negligence must have a greater than 50 per cent chance of having caused the claimant’s injury. When it is evidentially unclear to what extent the defendant’s negligence contributed to the outcome, the ‘but for’ test is modified and causation can be established through demonstrating a material contribution or increase to the risk of harm in a manner that is more than negligible.<sup>6</sup>

This chapter will highlight the problems posed by the ‘but for’ test in the genetic context and will also caution against characterising genetic risks as losses of chance, since this approach will exclude from the scope of the duty situations when the doctor’s negligence has a less than 50 chance of having caused injury. If the duty to disclose is not to be emptied of content, it is argued that the orthodox rules of causation should be relaxed and the causal link between nondisclosure and harm assessed as a material contribution to risk. It is acknowledged that orthodox causation is only relaxed when judicial policy and justice necessitate and this chapter proposes policy issues that support modifying the rules of causation in the context of the nondisclosure of genetic risks.

### *The ‘But For’ Approach*

The ‘but for’ test is the standard approach to assessing causation. The question before the court is essentially whether, on a balance of probabilities, ‘but for the defendant’s negligence would the claimant have been injured?’ The test, rather artificially, constructs causality as being either black or white. In plain terms, the defendant’s negligence must be more likely than not the cause of the claimant’s injury, a proposition that is generally unproblematic when concerned with physical harm. Thus the negligent driving example cited above would provide minimal controversy. Where an outcome would have eventuated despite the defendant’s negligence, causation is not established and the claim fails. This is the reason a widow was unable to recover damages in *Barnett v Chelsea and Kensington Hospital Management Committee*.<sup>7</sup>

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<sup>5</sup> *Ibid.*, at 372.

<sup>6</sup> See, for example, *Bonnington Castings v Wardlaw* [1956] AC 613, *McGhee v National Coal Board* [1973] 1 WLR 1, *Fairchild v Glenhaven Funeral Services* [2003] 1 AC 32, and *Bailey v Ministry of Defence* [2009] 1WLR 1052.

<sup>7</sup> [1969] 1 QB 428.

Here, three night watchmen attended a hospital's accident and emergency complaining of vomiting after drinking tea. The nurse on duty relayed the men's symptoms via telephone to the duty medical casualty officer who instructed her to tell the men to go home and consult their own doctors. Five hours after presenting themselves at the accident and emergency, one of the night watchmen succumbed to what was discovered to be arsenic poisoning, with the poison having been introduced into the tea. The deceased's widow brought an action in negligence against the hospital, alleging that his death would not have eventuated had he been attended, diagnosed and treated by the duty medical officer. The court accepted that the casualty officer had been negligent in not attending the night watchmen but concluded that, since the deceased would have died from arsenic poisoning even if the doctor had examined him, his death was not a result of the casualty officer's negligence. Therefore it could not be said that but for the defendant's negligence the night watchman would not have died. Causation could not be made out.

Causation, however, 'is not a strict technical matter which can be "solved" by the application of a quasi-mathematical formulae'.<sup>8</sup> Thus while the 'but for' test is a fairly straightforward proposition in claims concerning physical harm it becomes problematic in the medical context because 'there may be a variety of possible independent explanations for the occurrence of a condition.'<sup>9</sup> Thus it may not be clear which agent caused the injury, or it may be arguable that the cause is a preexisting state prior to the defendant's negligence.<sup>10</sup> Genetic information and risks add an additional layer of complexity to the question of causation because harm can always be characterised as flowing from either the defendant's negligence or the deleterious traits within the claimant's own genome. Thus it is not possible to confidently assert that, 'but for' nondisclosure, the condition would not have eventuated, since it is possible the condition occurred for reasons independent of the doctor's negligence. Where the condition would have eventuated in spite of any negligent intervention, the 'but for' test would see the claimant occupy a position analogous to *Barnett*, in that although there was negligence it was not causative of the injury.

The critical difficulty is that a doctor cannot be said to be the source of a genetic condition, irrespective of negligence. Genetic conditions are inherited disease, not

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<sup>8</sup> Mason, J.K., Laurie, G.T., *Mason & McCall-Smith's Law and Medical Ethics*, 9<sup>th</sup> ed. (OUP, Oxford: 2013), p. 158.

<sup>9</sup> *Ibid.*, p. 169.

<sup>10</sup> For example, see *Abada v Gray* (1997) 40 BMLR 116 and *Gates v McKenna* (1998) 46 BMLR 9. Both of these claims concerned individuals suffering schizophrenia allegedly precipitated by the defendant's negligence. In both cases, the court found no causal link between the defendants' conduct and the claimants' psychiatric condition.



contagious ones, thus the base reason why a condition has eventuated will always be the deleterious traits within the claimant's genome. Applying the 'but for' test to nondisclosure would adduce a conclusion that the claimant would have been injured despite the defendant's negligence. On a balance of probabilities, there would be no negligence *causing* harm. The nub of the issue is that a doctor's negligence is a failure to improve the claimant's prospects by enabling access to preemptive therapies. The harm is the eventuation of the undisclosed risk but the source of that risk is not the negligence per se. Thus attempting to establish causation using the 'but for' test would empty a duty to disclose of content because a causal link between negligent act and harmful outcome could not be established. Given that this approach would fail to recognise the impact of the defendant's negligence upon the genetic condition and render a legal obligation to disclose fairly meaningless, the 'but for' test must be viewed as an unsuitable means of establishing the causal link.

### *Loss of a Chance*

The 'but for' test is the standard approach to causation but, as demonstrated above, in the context of genetic nondisclosure it will be nigh impossible to satisfy, as the claimant's genes would be identified as the sole cause of their injury. Generally, causation is problematic in the medical context because 'there may be a variety of possible independent explanations for the occurrence of a condition',<sup>11</sup> as medicine is often an inexact science, a realm of possibilities and probabilities rather than certainties. In circumstances where two potential causal agents exist the question becomes, on a balance of probabilities, which was more likely the cause of the harm sustained. Causation is generally established on a balance of probabilities, however, in claims concerning physical injury the link between the defendant's negligent act and the claimant's harm is typically straightforward. Where the claimant's injury has two (or more) potential causes, the balance of probabilities determines whether or not causation can be established. This is particularly evident in claims relating to a loss of a chance. These types of claims are particularly significant in respect of nondisclosure because one way of conceptualising causation in this context is as a weighting of the significance of the defendant's negligence and the claimant's own genome.

Where two possible causes for an injury exist, for causation to be established the significance of the defendant's negligence must exceed the point of balance. In plain terms, it must be more likely than not that the defendant's negligence (and not something

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<sup>11</sup> Mason, Laurie, above, n 8, p. 169.

else) caused the claimant's injury. Statistically, therefore, the negligence must have a greater than 50 per cent chance of being the cause of the harm. When the negligence is significant enough that it surpasses the point of balance, it is treated as having caused the claimant's condition and full damages are recoverable. If another non-negligent cause surpasses the point of balance, the claimant can recover nothing even if the defendant acted negligently.

The balance of probabilities is thus an all or nothing threshold and its crude application in medical negligence claims is typified by litigation concerning the loss of a chance. The leading case in this regard is *Hotson v East Berkshire Health Authority*,<sup>12</sup> wherein the claimant – a 13-year-old boy – fell from a tree and damaged his hip. The defendants failed to correctly diagnose the boy's condition, which led to avascular necrosis in the hip joint and serious disability. There was, statistically, a 75 per cent chance that the disability would have developed even if the claimant had been correctly diagnosed and treated and, correspondingly, only a 25 per cent chance that a complete recovery would have been made. The trial judge and the Court of Appeal held that the claimant could recover damages equivalent to 25 per cent of his full loss but the House of Lords reversed the decision because the trial judge's finding of fact was that, on a balance of probabilities, the disability would have occurred in any event, meaning that the fall was the sole cause of the claimant's injury.<sup>13</sup> Thus although the defendant had acted negligently, their negligence had not caused the harm. If, on the other hand, the claimant had demonstrated a 51 per cent possibility of recovery prior to the defendant's negligence then he would have been entitled to recover the full amount of damages despite the fall from the tree constituting a 49 per cent contribution to the injury.

The House of Lords was provided an opportunity to revisit loss of a chance in *Gregg v Scott*.<sup>14</sup> The case concerned a negligent delay in the diagnosis of the claimant's lymphoma, which reduced the chances of recovery from 42 to 25 per cent. It was accepted that the original cursory examination of the patient was negligent, with the crux of the argument being whether a recognised harm had been caused. The claimant argued that the harm was the loss of the chance to survive more than ten years<sup>15</sup> (which was accepted, in medical terms, to mean a cure) or, as Lord Phillips and Baroness Hale perceived the issue,

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<sup>12</sup> [1987] AC 750.

<sup>13</sup> *Ibid.*, per Lord Mackay at 789-790.

<sup>14</sup> [2005] 2 AC 176.

<sup>15</sup> *Ibid.*, per Lord Hoffmann at 87.

the loss of a chance of a more favourable outcome to the claimant's prognosis.<sup>16</sup> The case was materially different from *Hotson* because 'the immediate spread of the cancer would probably not have occurred had there been prompt diagnosis ... [and] the developments which reduced his life expectancy were subsequent to the negligence',<sup>17</sup> whereas in *Hotson* falling from the tree damaged the claimant's hip joint and the negligent diagnosis meant that the damage was not recognised and treated. The claim might therefore have been articulated as a physical injury but, instead, it was couched as a loss of a chance of survival beyond ten years. Since the claimant's prospects had not exceeded the 50 per cent threshold prior to the clinician's negligence, the claimant could not satisfy the balance of probabilities. Lord Nicholls, in the minority, felt that the claimant's position before the negligence should not be determinative, arguing that when a patient is injured and suffers 'a significant diminution of his prospects of recovery by reason of medical negligence ... that diminution constitutes actionable damage' whether or not the patient's prospects before the negligence exceeded 50%.<sup>18</sup>

The majority, however, applied *Hotson* and rejected the claim. Baroness Hale 'relied heavily on policy concerns',<sup>19</sup> explaining that it would be problematic if claimants could submit lost chances as the basis of claims because 'almost any claim for a loss of an outcome could be reformulated as a claim for a loss of a chance of that outcome.'<sup>20</sup> This could lead to claims that would ordinarily be defeated being re-categorised as losses of chance, which would be extremely favourable to claimants because:

'he [the claimant] would recover 100 per cent if he proved on a balance of probabilities the loss of the outcome and would still recover something if he lost that argument but proved he had nonetheless lost some chance of a better outcome ... it "would be a 'heads you lose everything, tails I win something' situation".'<sup>21</sup>

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<sup>16</sup> *Ibid.*, per Lord Phillips at 125 and Baroness Hale at 226.

<sup>17</sup> Peel, E., Goudkamp, J., *Winfield & Jolowicz on Tort*, 19<sup>th</sup> ed. (Sweet & Maxwell: London, 2014), p. 287.

<sup>18</sup> *Gregg*, above, n 14, at 190.

<sup>19</sup> Stapelton, J., 'Loss of the Chance of Cure from Cancer' (2005) 68(6) MLR 996, p. 1002.

<sup>20</sup> *Gregg*, above, n 14, at 233.

<sup>21</sup> Maskrey, S., Edis, W., 'Chester v Afshar and Gregg v Scott: mixed messages for lawyers' (2005) 3 JPI Law 205, p. 213.

Lord Phillips and Lord Hoffmann also expressed concern about the consequences of allowing claims for loss of a chance and were of the view that ‘a departure from *Hotson* would change the basis of causation from *probability* to *possibility*, that is, that some form of recovery would be due if it was shown that it was *possible* that negligence might affect a patient’s case.’<sup>22</sup> Lord Phillips further cautioned that if special tests of causation were developed piecemeal to deal with perceived injustices the coherence of the common law would be ‘destroyed’.<sup>23</sup> But this reasoning is difficult to reconcile with the decision of the House of Lords in *Chester v Afshar*, where their Lordships willingly modified the rules of causation to vindicate the claimant’s interest in autonomy.<sup>24</sup> As Maskrey and Edis observe, it is possible to

‘look at the quartet of cases of *Fairchild*, *Chester*, *Gregg* and *MacFarlane*<sup>25</sup> and ask whether their Lordships have actually achieved their aim of creating or maintaining coherence within the common law.’<sup>26</sup>

The decisions in *Gregg* and *Chester* raise a further issue concerning the coherence, and importance, of patient ‘rights’ and it is difficult to see any coherent difference between ‘the right to decide whether to accept a particular treatment modality [*Chester*] and the right to be made in the first place aware of its existence and the possibility of its need [*Gregg*].’<sup>27</sup> The former right cannot be invoked unless the patient goes through the gateway of the latter, thus why should ‘the “right” to decide whether to accept treatment be accorded greater protection and value by the law than the logically and chronologically prior right to be told that such treatment is available and could be beneficial?’<sup>28</sup> The incoherence between *Chester* and *Gregg* is difficult to justify without concluding concerns regarding

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<sup>22</sup> Mason, Laurie, above, n 8, p. 162.

<sup>23</sup> *Gregg*, above, n 14, at 172.

<sup>24</sup> [2005] 1 AC 134. For a discussion of the decisions in *Chester* and *Gregg* see Green, S., ‘Coherence in Medical Negligence cases: a game of doctors and purses’ (2006) 14 Med L Rev 1. See also Maskrey, S., Edis, W., ‘*Chester v Afshar* and *Gregg v Scott*: mixed messages for lawyers’ (2005) 3 JPI Law 205.

<sup>25</sup> *MacFarlane v Tayside* [2000] 2 AC 59.

<sup>26</sup> Maskrey, Edis, above, n 21, p. 213.

<sup>27</sup> *Ibid.*, p. 222.

<sup>28</sup> *Ibid.*, p. 222.

the potential consequences of allowing claims for loss of a chance – the re-categorising of claims that would otherwise be defeated – was a powerful influence on the majority.

Lord Hope and Lord Nicholls dissented. Lord Hope thought that the claimant's case might actually be one of proved physical injury because the delay in diagnosis had led to the spread of the patient's cancer<sup>29</sup> and concluded the significant reduction in the prospects of a successful outcome 'is a loss for which the appellant is entitled to be compensated.'<sup>30</sup> If it was necessary to prove that the loss was caused by a physical injury, he felt the enlargement of the tumour was such an injury and, further, 'the principle on which that loss must be calculated is the same irrespective of whether the prospects were better or less than 50 [per cent].'<sup>31</sup>

Lord Nicholls argued that the all-or-nothing threshold of the balance of probabilities applied in *Hotson* was 'premised on a falsehood',<sup>32</sup> and lead to arbitrary outcomes, because it meant a patient with a 60 per cent chance of recovery reduced to a 40 per cent could obtain compensation but would 'obtain nothing if his prospects were reduced from 40 per cent to nil.'<sup>33</sup> Despite the claimant with an initial 40 per cent chance of recovery suffering a statistically greater loss than the claimant who originally had a 60 per cent chance, only the latter is able to recover damages in respect of negligent treatment or diagnosis. The problem for the claimant is that it must be more likely than not that the defendant's negligence caused their injury and in the former scenario, where the chances of recovery are 40 per cent, it is concluded as more likely than not the claimant's condition caused the harm.<sup>34</sup>

In the context of genetic risks, the loss of a chance may be articulated in one of two ways. First, it may be formulated as a loss of a chance of avoiding the condition outright; second, it may be argued that the claimant has suffered a loss of a medical intervention that would have helped them to avoid or minimise the condition. An analysis of lost chances

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<sup>29</sup> *Gregg*, above, n 14, *per* Lord Hope at 202-205.

<sup>30</sup> *Ibid.*

<sup>31</sup> *Ibid.*

<sup>32</sup> Mason, Laurie, above, n 8, p. 162, referring to *Gregg*, above, n 14, *per* Lord Nicholls at 43, where his Lordship explained the falsehood as being that 'a patient's prospects of recovery are treated as non-existent whenever they exist but fall short of 50 per cent'.

<sup>33</sup> *Gregg*, above, n 14, at 121.

<sup>34</sup> Although Stapleton argues that 'there is an important circularity to Lord Nicholls reasoning'. See Stapleton, above, n 19, p. 1003.

and genetic risks within the former context presents a claimant with a barrier analogous to that which prohibited recovery in *Hotson*. As Chico observes,

‘where there is a greater than 50 per cent chance that the claimant could have avoided the particular genetic condition if she had known about the risks, she could argue that the manifestation of the genetic condition itself constitutes harm.’<sup>35</sup>

Thus where the chance of avoiding the condition is less than 50 per cent, the balance of probabilities would weigh against the claimant as it did in *Hotson* – there would be no negligence causing harm. The problem for claimants is that ‘there are currently few genetic conditions which can be avoided’,<sup>36</sup> although therapies are available that can reduce the risks of certain conditions manifesting. The problem with formulating causation in these terms is that where the chances of avoiding the condition are too low, it will be concluded as more likely than not that the claimant’s genes and not the nondisclosure is the cause of the injury. The nondisclosure of genetic risks is not the source of the condition and formulating the loss of a chance as avoiding the condition means it is difficult to foresee the balance of probabilities favouring the claimant. Both *Hotson* and *Gregg* illustrate the problems here, as the fall from the tree and the lymphoma had a higher probability of causing the deleterious outcome than the doctors’ negligence. Even though the immediate spread of Gregg’s lymphoma may not have occurred if the original examination had not been negligent, it was always more likely than not that the cancer, and not the negligence, was responsible for the reduction in life expectancy. Therefore arguments concerning a loss of a chance to avoid a genetic condition are unlikely to meet with success. However, the debate in this respect does not seem to be completely settled as, in *Gregg*, Lord Phillips did accept that where ‘medical treatment has resulted in an adverse outcome and negligence has increased the chances of that outcome, there may be a case for permitting a recovery of damages that is proportionate to the increase’.<sup>37</sup> Lord Phillips did not believe that such a case was made out in *Gregg*; the question therefore is whether the loss of a chance to avoid the manifestation of a genetic condition may be such a case. Negligence in these circumstances could be characterised as increasing the chance of an adverse outcome (although, equally, it could be argued the claimant’s genes remain more likely than not the cause of harm) but whether the scenario

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<sup>35</sup> Chico, above, n 2, p. 143.

<sup>36</sup> *Ibid.*

<sup>37</sup> *Gregg*, above, n 14, at 225.

Lord Phillips envisaged is consistent with nondisclosure to persons beyond the therapeutic relationship is doubted.

An alternative means of articulating the loss of a chance in claims arising from nondisclosure is as a loss of a chance of receiving medical intervention, which might have reduced the possibility of the genetic condition eventuating. The emphasis here is not avoiding the condition but the loss of the opportunity to receive appropriate treatment for the condition that has eventuated. In this context, the nondisclosure and not the claimant's genome is what prevents them from seeking clinical advice and intervention. The court would therefore be faced with a threshold question of whether or not treatment has been denied by the nondisclosure. The presence of this gateway question would serve to limit the circumstances in which lost chances would be applicable and potentially restrict the opportunity to reformulate other negligence claims into lost chances, a concern that has typically dissuaded the courts from permitting arguments based on a loss of a chance. The restriction arises because the focus is on whether the negligence has denied access to treatment, which is distinct from an analysis focusing on the denial of a more favourable outcome, as this formulation could more readily be applied beyond a diagnostic context.

An argument might therefore be advanced that, providing any exception was narrow, the courts could dispense with the all or nothing position of the balance of probabilities that prevented recovery in *Hotson* and *Gregg*. The analysis of causation could be formulated as negligence causing a loss of a chance of treatment, which is a potentially black and white assessment of whether a particular course of therapeutic action was denied by nondisclosure. It is, however, unlikely that the courts would separate loss of a chance and analysis of statistical probabilities. Thus reconstituting the issue as a denial of treatment invites consideration of the effectiveness of available therapies.<sup>38</sup> This is not as disadvantageous as an argument based on avoidance of a condition because it is the success of the treatment that must surpass the point of balance and not the prospects of a disease not eventuating. However, it would continue to prohibit recovery when treatments are represented as having a lower than 50 per cent chance of alleviating a condition because the negligence would not cause the injury on a balance of probabilities.

It is likely that in some cases an argument could be advanced that causation is proved where a treatment successfully reduces the chances of a condition manifesting in 51 per cent of cases – or, alternately, is beneficial to 51 out of 100 patients. This would permit claimants to recover where nondisclosure had denied access to statistically

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<sup>38</sup> This may be a necessary element if a loss of a chance analysis is preferred, since it is arguable a claimant cannot lose a chance of receiving treatment if said treatment is ineffective or hard to come by.

promising treatments. However, the complexities of genetics and the possible advent of personalised medicine pose a problem since, if information is available (i.e. via pharmacogenomics) it could be argued before the court that while a treatment is generally successful in 51 per cent of cases, the particular claimant's genetics mean it would only have a 20 per cent chance of success. Evidence countervailing the broader statistics could lead to the balance of probabilities weighing against the claimant despite a notable success rate, indicating that relying on a loss of a chance of treatment may be problematic as increasing amounts of genetic information become available. Arguments premised upon a loss of a chance should therefore be treated with caution as they might prove to be an unfavourable means of establishing causation. If causation cannot be made out, then the duty to disclose becomes a worthless legal obligation, thus a more suitable means of assessing causation is necessary.

### *Material Contribution to a Risk*

In *Hotson* and *Gregg* the House of Lords declined to depart from the 'but for' test 'in response to the difficulty of proving causation in complex medical cases.'<sup>39</sup> However, their Lordships have demonstrated a willingness to innovate in a series of cases involving evidential uncertainty and exposure to toxic substances in the workplace. Firstly, their Lordships recognised liability when the defendant materially contributed to the claimant's injury. Here the question is not one of 'alternative causation, in which it is assumed that it is *either* the defendant's negligence *or* some other factor was *the* cause' of the claimant's injury,<sup>40</sup> but of 'cumulative' causation when both 'innocent' and negligent causes are held to have contributed.<sup>41</sup> Secondly, the House of Lords relaxed the orthodox rules of causation in the face of evidential uncertainty concerning the etiology of disease and accepted that liability is established when it is proved that a defendant materially contributed to the risk of injury.<sup>42</sup> Thus a claimant may establish a causal link between negligence and harm providing 'it can established that the negligence of the defender materially increased the risk of the claimant being damaged in the way in question.'<sup>43</sup>

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<sup>39</sup> Lunney, M., Oliphant, K., *Tort Law: Texts and Materials*, 5<sup>th</sup> ed. (OUP, Oxford: 2013), p. 221.

<sup>40</sup> *Ibid.*

<sup>41</sup> *Bonnington Castings v Wardlaw* [1956] AC 613.

<sup>42</sup> *McGhee v National Coal Board* [1972] 3 All ER 1008.

<sup>43</sup> Mason, Laurie, above, n 8, p. 169.



Assessing causation as a material contribution to risk is favourable to claimants as it does not require proof that the defendant caused the injury, merely that the negligence increased the risk of such. Applied in the context of nondisclosure of genetic risks, a material increase approach would address the problem created by the necessity of proof of cause in orthodox causation, since it cannot be said that a clinician is the source of a genetic condition. The harm in this context is the eventuation of the undisclosed risk,<sup>44</sup> not causing the disease per se. Thus nondisclosure could be characterised as materially increasing the risk of a condition eventuating, since access to preemptive therapies is denied. However, application of this approach to nondisclosure is problematic and certain barriers must be overcome if an argument in favour of a material increase approach is to stand.

The first difficulty to contend with is that the material increase approach is generally relevant where there exists evidential uncertainty and a sufficient evidential gap may not exist in nondisclosure. This is because genetic analysis is (ostensibly) a source of statistical probabilities associated with possessing specific genes. Reconciling nondisclosure of genetic risks with a causative paradigm based on evidential uncertainty would therefore appear problematic. Thus it might be suggested that conceptualising the issue as a loss of chance would appear the most appropriate way forward, although this returns to the problem of having to prove a greater than 50 per cent chance of avoiding a condition or receiving successful treatment prior to the defendant's negligence. A second hurdle to overcome is that the courts appear to have distinguished between material contribution to risk in an employment and medical context, thus causation was made out as a material increase in *McGhee v National Coal Board*,<sup>45</sup> an employment case, but the same option was not available to the claimant in *Wilsher v Essex Area Health Authority*.<sup>46</sup>

However, causation 'is not a strict technical matter which can be "solved" by the application of a quasi-mathematical formulae'<sup>47</sup> and engages 'matters of legal policy and justice'.<sup>48</sup> Thus judicial policy has motivated their Lordships to relax the orthodox rules of

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<sup>44</sup> Following cases such as *Chester v Afshar* [2004] UKHL 41 and *Birch v University College London NHS Trust* [2008] EWHC 2237. See chapter four for a full discussion of the concept of harm in claims for genetic nondisclosure.

<sup>45</sup> [1973] 1 WLR 1.

<sup>46</sup> [1988] AC 1074.

<sup>47</sup> Mason, Laurie, above, n 8, p. 170.

<sup>48</sup> *Ibid.*

causation ‘to prevent negligent employers from escaping liability on a technicality,’<sup>49</sup> and to give content to rights of patients to self-determination.<sup>50</sup> Thus, although at first blush it may appear problematic to apply a material increase test to nondisclosure, it can be argued that legal policy and justice necessitate relaxation of orthodox causation in the context of nondisclosure.

*Material Contribution to Risk, Genetic Nondisclosure and Judicial Policy*

The material contribution approach originally flows from the judgment in *Bonnington Casting Ltd v Wardlaw*.<sup>51</sup> Here the claimant suffered from pneumoconiosis – a lung condition – caused by inhalation of silica dust while working in the defendant’s foundry. There were two sources of the dust: a pneumatic hammer and swing grinders. The court accepted that the dust caused by the hammer did not amount to negligence because no measures were available to limit the exposure, but the dust extraction plant for the swing grinders was poorly maintained, often becoming choked and ineffective, which amounted to a breach of duty. The question for the court was whether the poorly maintained ventilation on the swing grinders was causative of the claimant’s condition. Lord Keith explained that it was for the claimant to ‘show that the dust released by their [the defendant’s] negligence from the swing grinders had contributed materially to the dangerous dust inhaled’.<sup>52</sup> The defendant’s contended that as there was no data available regarding the proportions of dust caused by the swing grinders and the hammers, the claim had to fail. Lord Keith, however, was of the opinion that the claimant had:

‘proved enough to support the inference that the fault of the defenders has materially contributed to his illness ... he has been exposed to a polluted atmosphere for which the defenders are in part to blame. The disease is a disease of gradual incidence. Small though the contribution of pollution may be for which the defenders are to blame, it was continuous over a long period. In cumulo it must have been substantial’.<sup>53</sup>

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<sup>49</sup> McIvor, C., ‘Debunking some judicial myths about epidemiology and its relevance to UK Tort Law’ (2013) 21 Med Law Rev 553, p. 558.

<sup>50</sup> *Chester v Afshar* [2004] UKHL 41.

<sup>51</sup> [1956] AC 613.

<sup>52</sup> *Ibid.*, at 626.

<sup>53</sup> *Ibid.*

The claimant therefore succeeded in his action because he was able to establish that the defendants had – on a balance of probabilities – materially contributed to his condition because the swing grinders’ extraction plant had been negligently maintained. Furthermore, the defendant’s contribution was more than negligible. Significantly for present purposes, that the claimant was exposed to a non-negligent source of silica dust and may have developed pneumoconiosis in any event was not fatal to the claim. In this respect an analogy can be drawn with genetic risks since there is also a negligent and non-negligent source of injury. A defendant may argue that because of the claimant’s genetic heritage they would have developed the condition in any event, however, it may also be argued that the failure to disclose the proband’s genetic information materially contributed to the onset of the condition where it has prevented access to treatment. The nondisclosure can be characterised as contributing to the eventuation of a condition if treatment is available because the negligence perpetuates a situation where the condition is more likely to occur, since access to preventative or minimising therapies is denied.

The decision in *Bonnington* can also be characterised as policy-driven in that it prevented the employer from escaping censure from substandard practice because of a technicality. Thus relaxing orthodox causation prevented an outcome that would have seriously undermined the validity employer’s duty of care to their employees. Rejection of the claim would have meant that the defendants could have continued negligently maintaining their foundry because the silica dust from the swing grinders was not established as *the* cause of the claimant’s injury. Therefore negligent practices that were likely to contribute to an outcome – but could not be characterised as causing that outcome – would have fallen through the cracks. In order to ensure a robust duty of care, it was necessary for the courts to uphold liability for the underlying mischief. Applying this logic to nondisclosure, it can be argued (in principle) that clinicians should not escape liability for failing to disclose risks to the proband’s blood relations merely because nondisclosure cannot be pinpointed as *the* cause of injury. If a duty to disclose is to be sufficiently robust – and achieve its aim – a relaxation of orthodox causation is arguably a necessity because of the difficulties in overcoming the causation hurdle.

This argument, of course, does not address the missing evidential certainty that generally engages a material contribution analysis, nor the distinction between the employment and medical context apparent in the case law, but an appeal to legal policy may represent a means of resolving these difficulties.

The question of contribution was considered again in *McGhee v National Coal Board*,<sup>54</sup> one of a number of policy-driven decisions representing ‘a direct response to the considerable difficulties that claimants can face when attempting to clear the causation hurdle.’<sup>55</sup> Here the claimant worked in a brick kiln, was exposed to brick dust and developed dermatitis. However, his actual exposure was not contested as being negligent, rather it was the defendant’s failure to provide onsite showering facilities which came under scrutiny, with the claimant alleging that this failure had materially increased his risk of developing dermatitis, since it meant he had to cycle home covered in dust. Evidence put before the House of Lords was inconclusive as to whether or not the exposure had caused the dermatitis, but evidence did suggest that the lack of after work washing facilities had materially increased the risk of the claimant contracting dermatitis. The evidential uncertainty in *McGhee* was therefore greater than in *Bonnington*, wherein the claimant’s disease was cumulative and the defendant’s negligence could be described as increasing the claimant’s prospects of developing a condition through increasing his exposure to the causal agent (although crucially the impact of the tortious silica could not be quantified).

However, despite this evidential gap, their Lordships found for the claimant, Lord Salmon stating that there was no distinction to be drawn between *Bonnington* and *McGhee*. He explained that it would be

‘unrealistic and contrary to ordinary common sense to hold that the negligence which materially increased the risk of injury did not materially contribute to causing the injury.’<sup>56</sup>

Again, the decision owed as much to policy as to pragmatism for as Lord Wilberforce – upon considering who should suffer the burden of the evidential difficulty – explained:

‘the answer as a matter of policy or justice should be that it is the creator of the risks who, ex hypothesi, must be taken to have foreseen the possibility of damage, who should bear its consequences.’<sup>57</sup>

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<sup>54</sup> [1973] 1 WLR 1.

<sup>55</sup> Mason, Laurie, above, n 8, p. 171.

<sup>56</sup> *Ibid.*, at 12.

<sup>57</sup> *Ibid.*, at 6.

Thus because the defendant increased the risk of an adverse outcome (in this case, dermatitis) it was just that providing the claimant could demonstrate – on a balance of probabilities – that the negligence had materially increased the risk of injury then causation was made out. A comparable argument might be made in respect of genetic risks, since the proband’s doctor possesses knowledge of the risks facing the claimant. Although it cannot be said the doctor is the source of the condition, nondisclosure increases the risk to the claimant since access to therapies is denied. If Lord Wilberforce is correct and those who create risk must bear evidential difficulties, then it might also be argued that those who possess knowledge of risks to others but fail to disclose these should also bear difficulties as a matter of policy.<sup>58</sup> In the context of genetics, the evidential difficulties do not relate to aetiology of disease, because genetics are usually a source of statistical probabilities associated with possessing a particular gene. Instead, the difficulties relate to proving nondisclosure is *the* cause of injury under orthodox principles of causation, which necessitates proof of a greater than 50 per cent chance of avoiding the disease or being successfully treated prior to the negligence. Since ‘prospects of recovery are attended with a significant degree of medical uncertainty’<sup>59</sup> the problem with relying on orthodox causation principles is that

‘the courts are engaged in an inevitably hypothetical inquiry about what *might have happened* if the doctor had not acted as she did, and this sort of speculation is not well suited to precise quantification in percentage terms.’<sup>60</sup>

These difficulties with establishing causation in cases of nondisclosure and the unsuitability of quantification in precise percentage terms reiterates the earlier point that causation ‘is not a strict technical matter which can be “solved” by the application of a quasi-mathematical formulae.’<sup>61</sup> In fact, attempts to do so may create injustice and the judiciary has shown a willingness to avoid such outcomes. In *Fairchild v Glenhaven Funeral Services*,<sup>62</sup> the House of Lords invoked policy considerations in finding for the

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<sup>58</sup> I.e. *Tarasoff v Regents of the University of California* 17 Cal. 3d 425 (Cal. 1976).

<sup>59</sup> *Gregg*, above, n 14, *per* Lord Nicholls at 190.

<sup>60</sup> Jackson, E., *Medical Law: Texts, Cases and Materials*, 3<sup>rd</sup> ed. (OUP, Oxford: 2013), p. 144.

<sup>61</sup> Mason, Laurie, above, n 8, p. 170.

<sup>62</sup> [2003] 1 AC 32.

claimant because, per Lord Bridge, '[a]ny other outcome would be deeply offensive to instinctive notions of what justice requires and fairness demands.'<sup>63</sup>

In *Fairchild*, the claimant had – throughout his working life – suffered multiple exposures to asbestos and as a consequence had developed mesothelioma. These exposures were negligent but a problem existed in that it was not possible to establish on orthodox principles of causation which among the claimant's employers had caused his injury. At the time, the prevalent theory regarding the aetiology of mesothelioma was that it could be caused by single 'rogue' fibre, rather than by accumulative exposures.<sup>64</sup> Consequentially, orthodox causation could not be satisfied because it demanded a causal link be established between one of many exposures and the claimant's mesothelioma. This link could not be made out because of the state of medical knowledge regarding the disease. The House of Lords was dissatisfied with an outcome that did not favour the claimant, because such 'would be deeply offensive to instinctive notions of what justice requires and fairness demands.'<sup>65</sup> Thus their Lordships turned to the principle established in *McGhee* and approved the judgement as a foundation of the proposition that proof of a material increase to risk can be sufficient to establish causation.<sup>66</sup> It was concluded that such an outcome was

'just and in accordance with common sense to treat the conduct of A and B [the defendants] in exposing C to a risk to which he should not have been exposed as making a material contribution to the contracting by C of a condition against which it was the duty of A and B to protect him'.<sup>67</sup>

Furthermore, their Lordships emphasised that '[p]olicy considerations weigh in favour of such a conclusion',<sup>68</sup> otherwise the claimants would have been 'thwarted through no fault of their own by the lack of scientific knowledge' and negligent employers would have

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<sup>63</sup> *Ibid.*, at 68.

<sup>64</sup> 'It seems that recently, and as noted by Lord Phillips in his speech in *Sienkiewicz* [[2011] UKSC 10 at 101], the "single rogue fibre" theory has become discredited in scientific circles.' McIvor, above, n 49, p. 557.

<sup>65</sup> *Fairchild*, above, n 62, at 68.

<sup>66</sup> *Ibid.*, per Lord Hoffmann at 75: 'in the particular circumstances, a breach of duty which materially increased the risk should be treated *as if* it had materially contributed to the disease.'

<sup>67</sup> *Ibid.*, per Lord Bingham at 68.

<sup>68</sup> *Ibid.*, per Lord Bingham at 68.

avoided liability on a technicality.<sup>69</sup> Thus it was established in *McGhee* and approved in *Fairchild* that ‘in particular circumstances, a breach of duty which materially increased the risk should be treated *as if* it had materially contributed to the disease’.<sup>70</sup> A further reason justifying a relaxation of orthodox causation in these cases is that a finding of no liability would have emptied the defendant’s duty of care of content. A result favouring the defendants would have meant they escaped censure for substandard practices, which would undermine the effectiveness of the employer-employee duty of care.

This relaxation of orthodox causation principles was most recently revisited by the Supreme Court in *Sienkiewicz v Grief*,<sup>71</sup> where the court adopted ‘a somewhat Janus-faced approach to it.’<sup>72</sup> The exception in *McGhee* and *Fairchild* was affirmed as applying ‘to give the claimant an action merely for the defendant’s creation of a risk that the deceased might contract mesothelioma’ but their Lordships ‘were at pains to point out it was exceptional.’<sup>73</sup> Although *Sienkiewicz* does not rule out the exception applying in contexts other than asbestos, it is noted that ‘the general tenor of the judgments suggests that any such attempt to extend the circumstances in which the rule applies will not be countenanced.’<sup>74</sup> Most notably, Lord Brown cautioned that courts should be ‘wary indeed’ of creating any additional special rules in personal injury.<sup>75</sup> This somewhat echoes the view of Lord Phillips in *Gregg* where he stated ‘if special tests of causation are developed piecemeal to deal with perceived injustices in particular factual situations ... the coherence of our common law will be destroyed.’<sup>76</sup> Yet despite Lord Brown’s skepticism towards special rules and Lord Phillips’ desire for coherence, it is possible to query whether coherence within the common law has been achieved<sup>77</sup> or causation is actually ‘in a state

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<sup>69</sup> McIvor, above, n 49, p. 558.

<sup>70</sup> *Ibid.*, per Lord Hoffmann at 75.

<sup>71</sup> [2011] UKSC 10.

<sup>72</sup> Lunney, Oliphant, above, n 39, p. 239.

<sup>73</sup> *Ibid.*

<sup>74</sup> *Ibid.*

<sup>75</sup> *Sienkiewicz*, above, n 71, at 187.

<sup>76</sup> *Gregg*, above, n 14, at 172.

<sup>77</sup> Maskrey, Edis, above, n 21, p. 213.

of flux'.<sup>78</sup> Legal policy and justice are influential factors in determining liability and, while fixed rules are to some extent preferred, policy considerations will occasionally necessitate departure from orthodox principles. This point is most graphically made by the outcome in *Chester v Afshar*, to which this chapter returns below.

The courts willingness to innovate in the context of diseases flowing from exposure during employment has not always been reflected in medical negligence claims. One reason for this may be the paternalism demonstrated towards the medical profession: causation based on 'alternatives' provides a measure of protection to healthcare practitioners, since it is for the claimant to prove on a balance of probabilities that the negligence – and not the underlying condition – caused the injury. A 'cumulative' approach would instead see causation made out providing the negligence made a more than negligible contribution to the harm. Stauch argues that a distinction between industrial diseases and medical negligence is necessary because, in claims involving the NHS, 'allowing recovery in doubtful causation cases will affect the resources available for other patients.'<sup>79</sup> Furthermore, he argues that in scenarios involving industrial diseases 'the claimant is exposed to risk factors that ... all ultimately derive from the workplace environment' but in the medical context 'the doctor intervenes on behalf of the patient to ward off natural risks ... and the treatment itself usually adds to the risks in play'.<sup>80</sup> The counterpoint to this is that a clinician should not avoid censure because a non-negligent source of injury also exists. If this were true, then the duty owed by a doctor to their patient would arguably be less onerous than the duty owed by an employer to their employees. Given the potentially significant impact of substandard practice in healthcare, the duty must be robust, but difficulties arise when there exists 'a variety of independent explanations for the occurrence of a condition.'<sup>81</sup>

The problem is typified by *Wilsher v Essex Area Health Authority*,<sup>82</sup> where a premature baby was administered excess oxygen and later developed retrolental fibroplasia (RLF), rendering him permanently blind. Evidence suggested that the excess oxygen

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<sup>78</sup> Mason, Laurie, above, n 8, p. 371. See also Hogg, M., 'Duties of care, causation and the implications of *Chester v Afshar*' (2005) 9 Edin LR 156 and Stauch, M., 'Causation and confusion in medical non-disclosure' (2005) 14 Nottingham LJ 66.

<sup>79</sup> Stauch, M., "'Material Contribution" as a response to causal uncertainty: time for a rethink' (2009) 68(1) CLJ 27, p. 29.

<sup>80</sup> *Ibid.*

<sup>81</sup> Mason, Laurie, n 8, p. 169.

<sup>82</sup> [1988] 1 AC 1074.



might have caused the claimant's RLF but there also existed four other potential causes of the condition. Citing with approval from the judgment of Sir Nicolas Browne-Wilkinson VC in the Court of Appeal,<sup>83</sup> Lord Bridge explained:

‘the occurrence of RLF following a failure to take a necessary precaution to prevent excess oxygen causing RLF provides no evidence and raises no presumption that it was the excess oxygen rather than one or more of the four other possible agents which caused or contributed to the RLF in this case.’<sup>84</sup>

Thus because the claimant could not demonstrate that the excess oxygen caused or contributed to the RLF, and four other possible explanations existed, the claim failed. The court was at pains to note that in circumstances where a condition had multiple explanations, there was no presumption in favour of the defendant's negligence. The decision, however, is ill at ease with the rule in *McGhee* and *Fairchild*, since it is fair to describe the administration of excess oxygen as materially increasing the risk of RLF in a way that was more than negligible. Furthermore, the existence of a non-negligent source was not fatal to the claims in either *Bonnington* or *Sienkiewicz*. The distinguishing feature in *Wilsher* therefore appears to be the uncertainty regarding which of the five possible agents caused the RLF. In contrast, *McGhee* and *Fairchild* only concerned single agents.<sup>85</sup> Litigation involving genetic information may thus be distinguishable from *Wilsher* because they involve a single agent – the genetic risk. In this respect, the position of the proband's blood relations is analogous to *Bonnington*, wherein the claimant was exposed to a non-negligent source of silica dust and may have developed pneumoconiosis in any event. The presence of this non-negligent source, however, was not fatal to his claim because the negligent source contributed in a manner more than negligible. Thus, in the context of genetic risks, it can be posited that because of their genetic heritage a claimant would have developed the condition in any event, but that a failure to disclose the proband's genetic information materially contributed to the onset of the condition because it prevented access to treatment. The nondisclosure contributes to the condition occurring if treatment is available because the negligence perpetuates a situation where the condition is more likely to eventuate, since access to preventative or minimising therapies is denied.

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<sup>83</sup> [1987] QB 730 at 779.

<sup>84</sup> *Wilsher*, above, n 82, at 1091.

<sup>85</sup> It was upon this basis that Lord Rodgers in *Fairchild* and Lord Hoffmann in *Barker v Corus* [2006] UKHL 20 distinguished *Wilsher*.

A departure from *Wilsher* may be further justified by the Court of Appeal decision in *Bailey v Ministry of Defence*.<sup>86</sup> Here the claimant had undergone an unsuccessful operation to remove a gallstone and, following the procedure, there was a lack of care and, in particular, a failure to resuscitate. The claimant was subsequently diagnosed as suffering from pancreatitis and transferred to an intensive care unit, then the renal ward, of another hospital, where she aspirated on her vomit, leading to cardiac arrest and hypoxic brain damage. The argument centred upon whether or not the defendants' lack of care had materially contributed to the claimant's weakened state, which left her unable to react to her own vomit. The trial judge held that defendants had materially contributed to the claimant's condition and the Court of Appeal upheld this finding, Waller LJ explaining that

'In a case where medical science cannot establish the probability that "but for" an act of negligence the injury would not have happened but can establish that the contribution of the negligent cause was more than negligible, the "but for" test is modified'.<sup>87</sup>

It therefore appears that the courts are beginning (albeit tentatively) to apply the *Fairchild* exception to claims beyond asbestos litigation. It may therefore be open to claimants in clinical negligence to establish causation where the defendant's negligence has materially contributed to the risk of harm eventuating. The proviso is that an evidential gap must exist. In *Bailey* the gap arguable took the form of the indivisible nature of the claimant's condition, in that it could not be deduced whether the pancreatitis or the negligence was *the* cause of injury, only that both contributed. In the context of genetics, there does not exist an evidential gap per se, since genetics tends to provide statistical chances associated with developing particular conditions. However, the difficulties posed by orthodox causation are advanced as justification for pursuing a relaxation of the 'but for' principle.

Assistance can be drawn from the decision in *Chester v Afshar*,<sup>88</sup> which concerned the nondisclosure of an inherent risk in spinal surgery.<sup>89</sup> The problem facing the claimant was that for causation to be made out she had to prove that but for the negligence – the failure to disclose the risk – she would not have undergone the operation and, thus, not

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<sup>86</sup> [2009] 1 WLR 1052.

<sup>87</sup> *Ibid.*, at 1069.

<sup>88</sup> [2005] 1 AC 134.

<sup>89</sup> Circa one per cent.

have been harmed. But she could not prove this, instead she could only prove she would not have had the operation *on that day*. All five of their Lordships agreed that the claim failed on a strict application of the law, but the majority were unable to accept this and argued the patient's right to self-determination required a remedy, relying on legal policy and justice to find for the claimant.

*Chester* illustrates of 'the House of Lords' willingness – albeit, in this case, by a majority only – to bend the rules of causation in the name of justice.'<sup>90</sup> The decision is distinct from *McGhee* and *Fairchild* because the risk to which the claimant was exposed was inherent in the operation and not a consequence of the negligence. The nondisclosure therefore had no impact upon the probability of the risk eventuating and could not be characterised as materially increasing a risk of harm. Thus *Chester* goes beyond the relaxation of orthodox causation in *Fairchild* and demonstrates that – where policy and justice dictate – the courts are willing to adopt a more holistic approach to causation, relaxing the orthodox principles where a merit worthy claimant faces considerable difficulties in overcoming the causation hurdle. The facts of *Chester* are not strictly analogous to circumstance involving genetic nondisclosure but there are some similarities. Most significant is that in neither scenario are the eventuating risks a product of negligence – the negligence is, instead, the failure to disclose the presence of such risks to the claimant. The negligence in *Chester*, however, did not impact upon the probability of the risk eventuating, whereas in cases of genetic nondisclosure the failure to disclose an identified, deleterious trait materially increases the risk of the condition manifesting because access to treatment is denied.

The important aspect of *Chester*, however, is its illustration of the courts willingness to relax orthodox causation to protect claimants' legally recognised interests and give content to a corresponding duty. In *Chester* the claimant had been injured because of an infringement of her interests in self-determination. Her doctor owed a duty of disclosure, the purpose of which was 'to enable adult patients of sound mind to make for themselves decisions intimately affecting their own lives and bodies'.<sup>91</sup> In failing to discharge this duty and respect the claimant's interests, the doctor harmed the claimant, but application of orthodox causation would have disclosed no remedy. By modifying causation, the House of Lords enabled negligence to vindicate the claimant's interests and provide content to the duty. Therefore despite rhetoric advocating coherence in the

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<sup>90</sup> Mason, Laurie, above, n 14, p. 158.

<sup>91</sup> *Chester*, above, n 88, *per* Lord Bingham at 5.

common law<sup>92</sup> and wariness in respect of special rules in personal injury<sup>93</sup> the courts are not averse to making policy-driven decisions in ‘direct response to the considerable difficulties that claimants can face when attempting to clear the causation hurdle.’<sup>94</sup>

Thus the difficulties facing claimants in cases of genetic nondisclosure may be viewed as sufficient justification for relaxing orthodox causation and adopting a material increase approach.

### *Reconciling Genetic Nondisclosure with Material Increase*

The difficulties establishing causation in cases of genetic nondisclosure reemphasises that causation ‘is not a strict technical matter which can be “solved” by the application of a quasi-mathematical formulae.’<sup>95</sup> In fact, attempts to do so may create injustice and the judiciary has displayed a willingness in cases such as *Fairchild*, *Bailey* and *Chester* to avoid such outcomes. The crux of the argument here is that by failing to disclose genetic risks to the proband’s blood relations a doctor materially increases the risk of a genetic condition eventuating. This is because nondisclosure denies access to preventative or preemptive therapies. Although genetic conditions are also a consequence of a deleterious trait in the claimant’s genome, the existence of a non-tortious agent does not preclude proof of causation. In *Bonnington* there existed two sources of the noxious agent, only one of which was negligent, but the contribution of the negligent source was deemed sufficient enough to have materially contributed to the harmful outcome. Of course an attempt can be made to distinguish *Bonnington* from claims arising from genetic nondisclosure on the basis it concerned a cumulative condition. The increase in exposure thus contributed to the probability of the adverse outcome eventuating, whereas failure to disclose a deleterious genetic trait is a failure to reduce the risk of a disease manifesting.

However, in *McGhee* the claimant’s exposure to brick dust (which was the likely source of his dermatitis) was not contested as negligent and the material increase was articulated as a failure to provide after work washing facilities. This can be interpreted as increasing the risk because it increased the claimant’s exposure to the brick dust (as he then had to cycle home covered in the dust), which is arguably consistent with the decision in *Bonnington*. However, the defendant’s wrongdoing may also be interpreted as,

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<sup>92</sup> *Gregg*, above, n 14, at 172.

<sup>93</sup> *Sienkiewicz*, above, n 71, per Lord Brown at 187.

<sup>94</sup> *Mason, Laurie*, above, n 8, p. 171.

<sup>95</sup> *Ibid.*, p. 170.

essentially, a failure to reduce the risk to the claimant. In other words, the defendants, by not taking steps that would have increased the claimant's prospects of avoiding dermatitis, materially increased the risk of the condition eventuating. Likewise, in *Bailey*, the negligent care can be described as failing to improve the claimant's post-operative condition. The care they received materially contributed to the claimant's weakened state, placing them at risk of further harm, which ultimately occurred because the claimant's weakness meant they were unable to react to their own vomit. The defendant in *Bailey* can also be described as failing to act to decrease the risk to the patient, although, notably, the case concerned a contribution to their general condition and not a specific disorder.

The causal link flowing from a material contribution does not, therefore, require a direct means of increasing risk, typified by the increased exposures in *Bonnington* and *Fairchild*. Causation can also be made out where the contribution is indirect, such as the failure to provide after work washing facilities in *McGhee*, which essentially amounted to a failure to decrease the risk posed by the claimant's non-negligent exposure to brick dust. In the context of nondisclosure, the deleterious gene is a non-tortious source of harm – akin to the brick dust – but the clinician's failure to disclose genetic information relevant to the condition increases the risk of the disorder eventuating because it denies the claimant access to medical treatment. For example, if the proband is identified as genetically predisposed to breast cancer and their relatives are not informed of the potentially shared risk, then family members are not able to seek either chemoprevention or surgical intervention. Should the claimant develop the disease then the nondisclosure has arguably made a material contribution to the outcome, in that the claimant was denied an opportunity to decrease the risk to their health. There is no fundamental difference between this scenario and one where the clinician fails to correctly diagnose a patient's cancer. In both circumstances the defendant does not cause the cancer but materially contributes to the development of the condition through their negligence.<sup>96</sup> Though one may suggest that the existence of the doctor-patient relationship alters the dynamic of the latter scenario, if a duty to disclose has been recognised by the courts then there should be no material distinction between the two sets of circumstances. The defendant's negligence has materially increased the risk in both.

Thus a material contribution approach to causation in claims of nondisclosure would appear consistent with existing case law on a factual basis. Although the majority

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<sup>96</sup> Arguably, had causation in *Gregg* been approached as a material contribution, then the House of Lords may have been more sympathetic to the claim. As it was, they were not persuaded by the claimant's loss of a chance argument. Lord Nicholls, in the minority, was certainly amenable to this argument.

of cases where a material increase analysis is applied are employment claims, *Bailey* demonstrates that clinical negligence is not immune to relaxation of orthodox causation. The decision in *Wilsher*, which eschewed a material increase approach, can be distinguished on the basis it concerns multiple casual agents, whilst genetic nondisclosure cases only concern the one: the deleterious genetic trait. A further hurdle exists, however, in that orthodox causation is only modified when a compelling policy reason exists. In cases concerning exposures at work, such as *Fairchild*, the relevant issue is the evidential gap resulting from scientific uncertainty on the aetiology of mesothelioma. It is not always necessary for there to be an evidential gap for the courts to relax orthodox causation, a fact demonstrated by *Chester* where it was not evidential difficulties that prevented the claimant satisfying the but for test but the fact she may still have proceeded with the operation at a later date. Thus she could not prove that but for the negligence she would not have been harmed because she would still have run the risk of spinal injury at some unspecified future point.

In both *Fairchild* and *Chester* the courts resolved the difficulties facing the claimants by relaxing orthodox causation on policy grounds. These grounds were discussed earlier in this chapter; the question for present purposes is what policy issue may justify relaxing orthodox causation in the context of nondisclosure of genetic risks. Two potential appeals to policy can be made in this respect. The first is that disclosure of genetic risks is in the public interest and, therefore, by providing a remedy for claimant's injured by nondisclosure the courts would be furthering those interests. If one interest is the right to life then relaxing the orthodox rules of causation could be argued as the court acting consistently with s6 Human Rights Act 1998, which places a duty on the court to act compatibly with ECHR rights. Provision of a remedy for an infringement of a claimant's Art 2 right could thus be presented as justifying departure from the but for test in the genetic context, although whether this is a likely route is certainly debatable.

A second appeal to policy could be made on the basis that if harm is recognised, the law must provide a remedy, for otherwise a duty could be emptied of content. In *Chester*, the eventuation of the undisclosed risk was the gist of the action and the majority recognised that adhering to orthodox causation denied a remedy to the claimant, which in turn stripped the doctor's duty to warn of content. Thus a relaxation of the orthodox rules was justified.<sup>97</sup> In *Fairchild*, recognition of mesothelioma as harm and the employer's duty of care would have been rendered inert by the difficulties posed by orthodox causation. An outcome that allowed the defendants to avoid censure for substandard

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<sup>97</sup> The interest in bodily integrity was also at stake in this context. See Stapleton, J., 'Occam's Razor reveals an orthodox approach to *Chester v Afshar*' (2006) 122 LQR 426.

practices on a technicality was inconsistent with justice and fairness,<sup>98</sup> thus causation was modified to enable proof of a causal link by material increase.

Both of these examples illustrate circumstances when a refusal to modify causation would have led to a situation where negligence recognised harm but did not provide a remedy. This was a position the House of Lords found to be unacceptable in both cases (albeit the majority only in *Chester*) because justice required the claimants' interest to be vindicated and the corresponding duty enforced. The eventuation of an undisclosed genetic risk has been argued as a harm grounded in an interference with the interest in bodily integrity. If this interpretation is recognised by the courts, then to vindicate the claimant's interest and give the correlative duty content, justice must require an available remedy. Recognising that a genetic condition eventuating is harm, and nondisclosure of the risk constitutes negligence, is moot if a claimant cannot prove a causal link. The problem facing claimants is that orthodox causation requires the clinician's negligence to be *the* cause of harm, not *one of* the causes of harm. If a claimant must prove on a balance of probabilities that negligence caused the genetic condition, the availability of a remedy will depend on a statistical lottery. Since medicine is an inexact science, imposing certainty is arguably disingenuous, as there often is none.<sup>99</sup> Moreover, if a particular behaviour and outcome is recognised as harmful, it follows that the law must provide a remedy if a duty is to have content. If harm is recognised but causation cannot be made out – because 'but for' the claimant's deleterious gene they would not have been injured – a duty to disclose would possess no content. Defendants would owe a duty to the proband's blood relations but in the vast majority of cases it would be unenforceable because the claimant could not evidence a causal link. In this event, the duty is rendered hollow; harm may be inflicted, a breach of duty may occur, but since the claimant cannot satisfy the balance of probabilities the defendant would avoid censure for substandard practice. This is arguably one of the reasons the courts modified causation in *Fairchild*, *Bonnington* and *McGhee*; in these cases, a finding of no liability would have rendered the employer's duty to their employees hollow because the obligation attracted no legal consequences. A duty would have been owed to provide a safe place of work but no liability would have accrued following a failure to uphold the appropriate standard of care. Thus the duty and the requisite standard of care would have been unenforceable because the defendant faced no consequences – put differently, the duty would fail in this context because the claimant was not provided a remedy.

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<sup>98</sup> *Fairchild*, above, n 62, per Lord Bridge at 68.

<sup>99</sup> See Tallis, R., *Hippocratic Oaths: Medicine and its Discontents* (Atlantic, London: 2004), chapter 4.

For a duty to disclose to possess sufficient content to be enforceable, a breach of duty must attract tangible consequences. When harm and nondisclosure occur it must not be impossible in the vast majority of cases for the claimant to prove causation, otherwise the duty will be rendered hollow. A sufficient prospect of liability must attach to the obligation or recognition of harm and negligent act become an empty gesture. Claimants will find it very difficult to satisfy orthodox causation because deleterious genetic traits, and not nondisclosure, can be portrayed as causing the harm. If harm could have been avoided or minimised by a timely disclosure, justice must require a remedy to vindicate the claimant's interests and provide content to the duty to disclose. Thus, it is argued as justifiable to relax orthodox principles of causation and allow claimants to prove nondisclosure materially increases the risk of harm.

### *Conclusions on Causation*

This chapter has explored the potential difficulties in proving causation should a duty to disclose be accepted by the courts. It has been established that the 'but for' test would disadvantage claimants because it focuses on the primary cause of injury. Therefore, in the context of genetic risks, it could be fairly argued that harm would not have occurred but for the claimant's deleterious genetic trait. The problem is typified by the decision in *Barnett v Chelsea and Kensington Hospital*, which concluded that since the claimant would have died from arsenic poisoning in any event, the doctor's negligence was not a causal agent of the harm. If such an approach were applied to claims concerning a duty to disclose then there is a real risk that it would empty the duty of content because it would be virtually impossible to establish a causal link between the harm and the negligent act.

Causation may alternatively be approached as a loss of a chance and it is for the claimant to establish, on a balance of probabilities, that the defendant more likely than not caused the harm. This has led to a dichotomy between individuals whose initial chances of avoiding injury are above and below the point of balance. Thus, those whose original chances of avoiding harm were greater than 50 per cent are able to recover in full, but those whose chances were below 50 per cent are unable to establish a causal link between the defendant's negligence and their injury. The courts are particularly reluctant to allow claims for a loss of a chance because this may lead to claims that would otherwise fail being re-categorised and succeeding, which may unduly favour claimants and overly burden defendants. Thus in the context of genetics, the balance of probabilities would require proof of a greater than 50 per cent chance of avoiding a genetic condition of being successfully treated, restricting application of a duty to disclose to those scenarios where potential outcomes can be adduced with sufficient certainty. But medicine is an inexact



science and applying orthodox causation would allow substandard practice to avoid censure because of a technicality.

If the loss of a chance is characterised as avoiding a genetic condition a problem arises in that few genetic conditions can, at present, actually be avoided. Thus it has been suggested, in the alternative, that causation could be assessed as a lost chance of successful treatment, which could potentially create a platform for reconsidering loss of a chance arguments as the availability of treatment acts as a threshold question. It is unlikely, however, that the courts would be receptive and thus the courts would likely consider the potential benefits of treatment and whether, in percentage terms, available therapies would have altered the claimant's prognosis. Again, this would restrict application of the duty to circumstances where there is certainty of a cure. In reality – for example, in the case of individuals at risk of cancer – treatment rarely offers a guarantee of cure but early diagnosis and preemptive treatment improves an individual's prognosis and may present opportunities to minimise the condition that late diagnosis would not.

Finally, this chapter explored causation as a material contribution or increase to a risk of injury. It has been argued that relaxing orthodox causation may be appropriate and that the evidential difficulties facing claimants in cases of genetic nondisclosure may be viewed as sufficient justification for relaxing orthodox causation and expanding the rule in *McGhee* and *Fairchild*. Orthodox principles of causation require proof of a greater than 50 per cent chance of avoiding the disease or being successfully treated prior to the negligence. However, the doctor does not cause the claimant's disease per se but increases the risk of it eventuating, since the failure to disclose denies access to preemptive treatment.

It has been argued that cases such as *McGhee*, *Fairchild*, *Bailey* and *Chester* illustrate that the courts are willing to make policy-driven decisions in response to 'the considerable difficulties that claimants can face when attempting to clear the causation hurdle.'<sup>100</sup> *Chester*, in particular, illustrates that the courts are willing to adopt a more holistic view of liability and modify the rules of causation in the interests of justice, particularly where orthodox principles would empty a duty of content.

In the genetic context, a material increase can be characterised as either direct following *Bonnington* (wherein negligently maintained ventilation increased the claimant's exposure to the noxious agent) or indirect as per *McGhee* (where a failure to provide showers was held to materially increase the risk of the claimant developing dermatitis). Furthermore, the rule in *McGhee* and *Fairchild* has been applied to medical negligence in *Bailey v Ministry of Defence*, thus it appears open to claimants to establish causation on the

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<sup>100</sup> Mason, Laurie, above, n 8, p. 171.

basis the defendant's negligence has materially increased the risk of harm. In *Bailey* this material increase amounted to the weakening of the claimant's physical condition through poor care, meaning they were later unable to react to their vomit and asphyxiated. It may thus be possible to establish causation in claims of nondisclosure by demonstrating negligence materially increases the risk of a condition eventuating because nondisclosure denies access to preventative treatment.

Adopting this approach is argued as significant if a duty to disclose is to have meaning, since an application of the orthodox 'but for' approach would invite a finding that 'but for the claimant's genes they would not have become ill' unless a difficult statistical threshold could be met. This would strip a duty to blood relations of meaningful content. Applying the rule in *McGhee* and *Fairchild* may therefore be justified if a duty to disclose is to be more than an empty gesture.

## CONCLUSION

Genetic information is simultaneously personal and familial. The results of a patient's genetic screening are indicative of the genetic heritage of both that individual and their blood relations. For this reason, healthcare practitioners will find themselves in possession of information that is relevant to the health of individuals beyond the traditional doctor-patient relationship. Where the identified conditions or susceptibilities are treatable, there is a benefit in disclosing the proband's genetic information to their relatives. An important question is how the law will react to the familial properties of genetic risks. The judiciary could restrict disclosure and uphold doctor-patient confidentiality and data protection or recognise disclosure as a method of preventing harm in appropriate circumstances.

The core argument of this thesis has been that disclosure should be obligated where treatments are available for genetic conditions. One example is where a risk of breast cancer is identified in the proband's genome. As early intervention is beneficial to individuals at risk of this condition, disclosure of a genetic risk would facilitate timely access to screening and therapies or surgical interventions, such as chemoprevention or a double mastectomy. Facilitating access to preventative therapies or early diagnosis and treatment is (self-evidently) beneficial to the long-term health of family members; where no treatment exists, the risk of psychiatric harm arguably prohibits disclosure. Disclosure of genetic information may also benefit the economic position of healthcare providers, who may be able to offer cheaper, preventive therapies and facilitate a reduction in the number of patients undergoing costly, invasive treatments. An illustration of the possibilities is provided by tamoxifen, a drug that can reduce the risk of breast cancer, which costs approximately £130 for a five-year course for a single patient; treatment for a patient suffering breast cancer will cost around £60,000 for the equivalent period.

This thesis argues an appropriate means of achieving disclosure is through creating a tortious duty. It is argued the requirements of liability in negligence – duty, breach and causation – can be made out where a doctor fails to disclose genetic risks to the proband's blood relations. In respect of duty, the three elements of the *Caparo* test – foreseeable harm, proximity and fair, just and reasonable – can be satisfied. Foreseeable harm has been presented as the eventuation of the undisclosed genetic risk; drawing upon UK and US case law it is argued that defendants do not have to be the source of the claimant's injury for actionable harm to exist. This is evident in claims concerning nondisclosure of risk such as *Chester v Afshar*, *Tarasoff v Regents of the University of California* and *Safer v Estate of Pack*, wherein adverse outcomes the defendants were not the source of formed the gist of the actions. In these cases, none of the defendants created the risks facing the claimants – they, instead, arose from a non-negligent operation, an ex-boyfriend and a

genetic trait respectively – but because a disclosure was not made, the defendants were liable for the adverse outcomes, as these might otherwise have been avoided or minimised had a timely disclosure been made. Though clinicians are not the source of a genetic condition – this is claimant’s biological heritage – harm occurs when an undisclosed, treatable risk eventuates. It is argued the failure to disclose infringes the claimant’s interest in bodily integrity, thus the harm is the physical burden nondisclosure could have prevented or minimised. As an illustration, if the proband is identified as genetically predisposed to breast cancer, the options available include chemoprevention or a double mastectomy. If this diagnosis is disclosed to their blood relations the same options become available to those individuals; if that risk is withheld, and the claimant develops cancer, harm is inflicted because disclosure would have facilitated access to these therapies, which could have prevented or reduced the risk of the condition occurring.

The question of proximity is also surmountable. Traditional approaches to proximity are based on physical closeness or the existence of an antecedent relationship, but these are inapplicable in this context because blood relations are third parties. However, a relationship of sufficient neighbourhood can be established if it is demonstrable that the claimant is an identifiable victim of the defendant’s negligence. This approach to proximity was most famously applied in the American case of *Tarasoff v The Regents of the University of California* and has also been applied genetically transmissible diseases in *Safer v Estate of Pack*. Domestically, support for an identifiable victim approach can be drawn from *Palmer v Tees Health Authority*, *W & Others v Essex County Council* and *Selwood v Durham County Council*. Who is an identifiable victim in the genetic context is deduced by reference to straightforward degrees of consanguinity, which dictate who is at the highest risk of ‘sharing’ a deleterious genetic trait identified in the proband’s genome. It is thus possible to deduce the identity of the potential ‘victims’ of deleterious genetic traits and take the most suitable precaution – namely to disclose the presence of the genetic risk – which, in turn, provide access to diagnostic screening and treatment.

Potential policy issues that may militate for or against a duty to disclose have also been explored,<sup>1</sup> including doctor-patient confidentiality and the risk of psychiatric injury, but it is argued here that none prohibit a duty existing. Instead, these policy issues can be overcome if a duty to disclose is developed with fair and sensible boundaries. Thus the duty to blood relations must not be developed in a manner which undermines doctor-patient confidentiality, but in a way that restricts the proband’s interest only to the extent

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<sup>1</sup> For a full discussion of the various policy issues, see chapter three.

necessary to facilitate disclosure of treatable genetic risks. If disclosure is consistent with a public interest and thus represents a justifiable infringement upon confidentiality and data protection, the duty to disclose would be consistent with the legal paradigm governing the processing of medico-personal data.<sup>2</sup> The objection that disclosure may actually inflict psychiatric harm can be rebutted on the basis that disclosure would only be obligated when treatments are available for the identified genetic condition. In these circumstances the risk of psychiatric harm occurring would be countervailed by the possibilities of treatment. It is acknowledged that in circumstances where no therapies are available, such as in cases of Huntington's disease, the risk of disclosure causing harm is prohibitive, and it is argued that the availability of treatment is critical limitation on the scope of a duty to disclose. Thus a duty would not arise in circumstances where no treatment exists for the genetic condition; in this context, the possibility of disclosure inflicting harm would not be outweighed by therapeutic interventions, therefore the benefits of making disclosure to facilitate preparedness are not considered to be compelling.

This thesis also considers the questions of breach and causation and how these may apply in claims arising from the nondisclosure of a patient's identified genetic risks. In respect of breach, it is argued that applying *Bolam* may pose difficulties because of the courts' reluctance to choose between divergent bodies of medical opinion. It is therefore possible for nondisclosure to be non-negligent conduct if it is conduct consistent with the views of a responsible body of medical opinion. These difficulties may be overcome if the judiciary is willing to engage the qualification from *Bolitho* and examine whether an opinion supporting nondisclosure withstands 'logical analysis'. It is argued here that it is appropriate to scrutinise the risks and benefits inherent in a decision to, or to not, disclose and whether these are properly weighed in the circumstances. It is also suggested that while the judiciary appear reluctant to apply *Bolitho* in circumstances involving complex and technical medical issues, there may be an increased willingness to find a body of medical opinion does not withstand logical analysis if the matter is accessible to a lay person. Thus the courts may be more willing to reject a body of opinion as illogical in claims concerning nondisclosure because the decision whether or not to warn is, arguably, not technically complex. In the alternative, it is proposed that breach could be assessed by means not dissimilar to those applied in cases concerning doctor-patient disclosure. The question of breach in these cases is couched in terms of whether a risk was sufficiently serious that the reasonable person would want to have known about it in the circumstances. What constitutes a sufficiently serious risk is unclear and seriousness may be assessed

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<sup>2</sup> See chapter two for a full discussion of public interest justifications, confidentiality and data protection.

either through the statistical likelihood of an outcome eventuating, the severity of the potential outcome, or a combination of the two. Some genetic risks are thus likely to fall within the scope of such a test but whether such an approach would be consistent is uncertain. Assistance might be drawn from the recommendations of the American College of Medical Genetics and Genomics on the reporting of incidental findings during genetic screening, as these the recommendations focus on disclosing treatable risks. There is, however, a residual question regarding whether doctor-patient disclosure cases have actually moved away from applying *Bolam*, thus arguments drawn from this vein of case law must be considered cautiously in light of the forthcoming Supreme Court decision in *Montgomery v Larankshire Health Board*. If the Supreme Court affirms the trajectory the case law appeared to be taking, then failing to disclose a treatable genetic risk may lead to a breach of duty. If the Supreme Court restates *Sidaway* as the leading authority on disclosure, genetic nondisclosure may instead fall within *Bolam-Bolitho*.

In respect of causation, it is argued that the ‘but for’ test is incompatible with claims concerning nondisclosure of genetic risks. This is because, should a duty be upheld, a ‘but for’ analysis may legitimately find that harm would not have occurred to the claimant ‘but for’ their deleterious genetic heritage. This would mean liability would be impossible to make out and it would leave any duty to disclose empty of content. Since nondisclosure involves two potential causal agents – the nondisclosure and the genetic risk – it is likely the courts will adopt a loss of a chance analysis of causation drawing upon *Hotson* and *Gregg v Scott*. Loss of a chance is problematic because the original chance must have been, on a balance of probabilities, more likely than not to occur prior to the defendant’s negligence. In statistical terms, a claimant must have had a greater than 50 per cent chance of avoiding an adverse outcome; if the original chance is below the point of balance, it is considered certain that the adverse outcome would have eventuated in any event, despite the defendant’s negligence. Therefore a loss of a chance analysis will require the initial probability of a claimant avoiding a genetic condition to be greater than 50 per cent, but, as has been noted, few genetic conditions can de facto be avoided. An alternative analysis would be to restrict the statistical enquiry to whether or not the nondisclosure has resulted in the claimant losing a chance of treatment. A preference is expressed for a black or white analysis, but it is likely the courts will not separate loss of a chance and statistical probabilities, thus focusing on treatment would lead to an analysis of the chances of therapeutic success. This is more favourable than focusing on avoiding the condition but is still restrictive in that it requires a greater than 50 per cent chance of successful treatment. Since medicine is an inexact science, adducing success with certainty is difficult and thus any loss of a chance approach should be viewed with caution,

for it may overly restrict application of a duty to disclose. The approach to causation preferred in this thesis is an assessment based upon a material contribution to risk, drawing upon the decisions in *Bonnington Castings v Wardlaw*, *McGhee v National Coal Board*, *Fairchild v Glenhaven* and *Bailey v Ministry of Defence*. The question here is whether or not nondisclosure contributes to, or increases, the risk of a genetic condition eventuating, in a way that is more than negligible. It is acknowledged there are problems with adopting this approach but it is argued that these can be overcome by an appeal to policy. If a material increase approach is adopted, causation will be established if nondisclosure denies the claimant access to preventative therapies or early diagnosis and treatment, thereby increasing the probability of the genetic condition manifesting. Thus returning to the example of the familial risk of breast cancer, a failure to disclose materially increases the risk of the condition eventuating, because the cancer could have been avoided or minimised by chemoprevention or surgery.

Genetic screening offers an opportunity to tackle diseases through preventative therapies or early diagnosis and treatment. For this reason it is important to recognise genetic information is familial in nature and, thus, relevant to persons other than the proband. In order to recognise that relatives' are harmed by nondisclosure of genetic risks, it is necessary for the law balance the familial benefits of disclosure with the proband's interest in doctor-patient confidentiality. The current paradigm of confidentiality and data protection is ill equipped to recognise the familial aspects of genetic screening and a change in the law is necessary if the interests and long-term health of the family are not to be overlooked. This thesis argues that an appropriate means of achieving protection for the proband's blood relations is through recognition of a duty to disclose genetic risks. The tort of negligence has previously been a route through which novel claims concerning nonphysical injury have achieved recognition<sup>3</sup> and it is argued here that negligence may again be the appropriate means by which to litigate claims arising from the nondisclosure of a patient's deleterious genetic traits.

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<sup>3</sup> For example, psychiatric injury.

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