Article

MEDICAL LAW INTERNATIONAL

Medical Law International
2016, Vol. 16(1-2) 3–26

DOI: 10.1177/0968533216653440
mli.sagepub.com
SAGE

Non-disclosure of genetic risks: The case for developing legal wrongs

Victoria Chico
University of Sheffield, UK

Abstract
In *ABC v. St Georges Healthcare NHS Trust*, the High Court of England and Wales rejected the argument that doctors have a legal duty to disclose actionable genetic risks to a patient's relatives. This article reconsiders the concept of a duty to disclose actionable genetic risks in the context of widening perceptions of legal harm and developing professional and public perceptions of corresponding wrongs.

Keywords
Genetic risk, non-disclosure, legal harm, legal wrong, confidentiality

Introduction

When should information about future genetic risks be disclosed to a patient's unsuspecting relative? This question has troubled genetics professionals for over a decade.[1] However, the question of whether a clinician owes a legal duty of care to disclose a genetic risk to a patient's relative was not considered by the English courts until May last year in *ABC v. St Georges Healthcare NHS Trust.*[2] This case presented a particularly

1. K. Offit, E. Groeger, S. Turner, et al., 'The ''Duty to Warn'' a Patient's Family Members About Hereditary Disease Risks', *Journal of the American Medical Association* 292 (2004), pp. 1469–1473.
2. *ABC v. St Georges Healthcare NHS Trust* [2015] EWHC 1394 (QB).

Corresponding author:
Victoria Chico, School of Law, University of Sheffield, Bartolome House, Sheffield S3 7ND, UK.
Email: v.chico@sheffield.ac.uk

difficult legal challenge because it concerned a number of competing interests affecting patients, their relatives and the health professionals who care for them. Nevertheless, on the facts of *ABC* there was neither an established legal wrong nor an established legal harm, thereby making it relatively easy for the judge to reject the claim on the basis that any extension of the duty of care would amount to more than an incremental development which was contrary to the way in which the law of negligence ought to progress.[3] This article considers the implications of imposing a duty to disclose actionable genetic risks to relatives in a more developmental context, which it is argued more accurately reflects the values of the patients, relatives and doctors involved.

The article begins with a discussion of the relationship between 'wrong' and 'harm' in the context of the tort of negligence. This discussion is particularly important in cases such as *ABC* where the analysis focused on the issue of whether there was a legal wrong in the context of a situation where there was no established legal harm. Following this discussion, the article separates the concepts of legal wrong and legal harm, and analyses how developments in the law, professional genetic practice and in the empirical evidence of public opinion might lead one to question the judge's reliance on traditional approaches which do not appear to reflect current values in this context. Towards this aim, the article discusses developments in the recognition of legal harm in the reproductive context. It is argued that the existence of a legal wrong in frustrated reproductive choice cases has influenced development of the recognition of novel legal harm. This article analyses how the harm alleged in *ABC* might map onto this existing legal doctrine. After arguing that the existence of a legally recognized wrong can influence the development of a legally recognized harm, the article then addresses whether the converse is also possible; in other words, whether the existence of legal harm can similarly influence the development of novel legal wrong. This analysis is more pertinent to the result in *ABC*, which focused on the lack of a legal wrong in the context of non-disclosure of genetic information to relatives. Here the discussion focusses on the policy reasons which were employed in the case to deny that doctors owe a duty of care. The traditional view that patient confidentiality should be paramount and that the right not to know should be protected by default are challenged as out of touch with genetic professionals, patients and the public's views regarding the sharing of genetic information within families. The article argues that professional, patient and public attitudes to genetic information sharing are evolving such that there is a widening perception that a failure to disclose actionable genetic information is a wrong which can lead to actionable harm. Where the law does not reflect public and professional values, we might question adherence to incrementalism that prevents the law from reflecting these values. As Jane Stapleton acknowledged many years ago, areas of the law which have developed incrementally tend to be areas where the 'silliest rules' now exist and where 'criticism is almost universal'.[4]

3. *ABC*, para 13.
4. J. Stapleton, 'In Restraint of Tort', in P. Birks, ed., *Frontiers of Liability.* Vol. 2 (Oxford: Oxford University Press, 1994), p. 95.

Background

The essence of the tort of negligence is a wrong which leads to a harm. Both of these elements have historically been essential to establishing a claim. There is no such thing as negligence in the air such that, no matter how carelessly a person acts, they have not breached their duty to another and thus it might be argued that there is no legal wrong that could be recognized in the tort of negligence. On this perspective, there is no stand-alone duty to be careful.[5] However, some commentators take a different view of duties of care in negligence, according to which if A owes B a duty of care of some description, A will actually have a legal duty to be careful.[6] McBride describes holders of the former view as cynics and the latter as idealists. According to the idealistic view of duties of care in negligence, if A is said to owe B a duty to take care not to do X in a given situation, A will have a primary obligation to take care not to do X such that there is intrinsic wrong if he does do X. If B also suffers a loss as a result of A doing X, he will usually incur a secondary obligation to pay damages to B.[7] The cynical view requires us to work backwards from the harm such that the existence of a harm influences the recognition and, consequently the development of the concept of legal wrongs. This distinction between cynics and idealists becomes more difficult to describe where there is an adverse outcome, but it is not one which the law recognizes as harmful. Here the conclusion that there is no harm and that the carelessness does not therefore amount to a wrong might seem unduly unfair to the victim, especially if the outcome is one which the other party was actively employed to prevent. In these circumstances, the idealistic view of duties of care might be favourable even if it leads to the conclusion that the claimant suffered a legal wrong but they will not receive compensation for it because the law does not recognize the particular outcome as harmful. The relationship between wrong and harm in developing duties of care in negligence was particularly pertinent in *ABC* where neither carelessness nor harm could be easily established.

ABC v. St Georges Healthcare NHS Trust

The claimant in *ABC* was a woman whose father had shot and killed her mother in 2007. He was convicted of manslaughter on the grounds of diminished responsibility and sentenced to a hospital order under the Mental Health Act 1983. In 2009, the claimant's father received a diagnosis of Huntington's disease. Huntington's disease is a serious progressive neurodegenerative genetic condition. If a parent is affected, there is a 50% chance that his or her child will also be affected, but onset is not until adulthood. Thus there was a 50% chance that the claimant also had the Huntington's disease gene. The

5. D. Priel, 'Tort Law of Cynics', *Modern Law Review* 75 (2014), p. 703; P. Cane (ed.) *Atiyah's Accidents, Compensation and the Law* (Cambridge: Cambridge University Press, 6th ed, 1999), p. 58.
6. N. McBride, 'Duties of Care – Do They Really Exist?', *Oxford Journal of Legal Studies* 24 (2004), pp. 417–441. I would to thank one of the anonymous reviewers for highlighting the relevance of this literature.
7. N. McBride, 'Duties of Care'.

health professionals looking after the father sought his consent to disclose his diagnosis to his daughter, which he refused. No attempt was therefore made to inform the daughter, who was pregnant at the time, of her risk or the risk to her unborn child. Following the birth of her child in 2013, the claimant was diagnosed with Huntington's disease. Her daughter has not been tested as it is contrary to usual medical practice to test for this adult onset genetic mutation in childhood. However, given that the claimant has the disease, there is a 50% chance that her daughter possesses the gene.

The claimant alleged that the failure to tell her about her father's condition was actionable negligence and a violation of her rights under Article 8 of the European Convention on Human Rights. The focus here is on the action in negligence, where the claimant portrays her harm as having arisen from the failure to have the opportunity to choose an abortion.[8] She argued that had she been informed of her father's condition she would have undergone genetic testing. Once this showed positive she would have chosen to terminate her pregnancy. The claimant alleged that if her daughter did have the gene, she would incur expenses which could have been avoided. For a number of reasons this claim was difficult to establish. First, the outcome suffered by the claimant is not established as a legally recognized harm. Furthermore, irrespective of the outcome, it is not currently recognized to be legally wrong to fail to warn a patient's relatives of genetic risks. Such claims are further hampered by the fact that, if a duty did exist, it may come into conflict with the well-established duty to maintain patient confidentiality. However, *ABC* represents one example of a number of potential non-disclosure grievances where legal wrong and/or legal harm could be more easily established. Furthermore, the case comes at a time of rapid development in genetic medicine, and in the way that genetic professionals perceive patients and families, which reflects wider perceptions of what is considered wrongful.

Legal interpretations of wrong and harm in frustrated reproductive choice

English law recognizes the importance of reproductive choice. Article 12 of the European Convention on Human Rights recognizes that people have the right to found a family. The Human Fertilisation and Embryology Act 1990 also recognizes that to some extent people should be able to choose the characteristics of their children.[9] On the other hand, the choice not to have a child is recognized. A woman can choose to abort a foetus on a number of grounds,[10] or undergo sterilization so as not to have any, or any more, children. Failure to respect these reproductive rights can constitute a wrong which would be a breach of a duty of care. However, these reproductive interests crystallize in the context of relationships. A healthcare practitioner will owe a duty to respect a person's

8. The claimant also alleged psychiatric harm although no evidence of this was presented in the case. The psychiatric harm claim is not considered here as it is the focus of an extended case comment I have written; V. Chico, 'Doctors Under No Duty to Warn Patients' Relatives of Genetic Risks', *Professional Negligence* 32 (2016), pp. 82–85.
9. Human Fertilisation and Embryology Act schedule 2 1ZA.
10. Abortion Act 1967 s 1 (1) (a), (b), (c) and (d).

reproductive choices where he or she has undertaken to assist the person with their reproductive aim. It is not similarly an act of wrongdoing for doctors to fail to seek people out to assist them with their reproductive aims. Thus the claimant in *ABC* had not been subjected to any legally recognized wrong when the reproductive risk information was not disclosed to her. Furthermore, the essence of the claimant's cause of action was that she had a daughter who she would have elected not to have if she had known about her, or her daughter's, genetic risk.[11] In addition to the absence of a legal wrong, the framing of the harm in terms of the birth of a child is problematic, as this is not an outcome that the courts clearly categorize as legally actionable harm. For the legal cynics, this lack of harm will support the argument that even if the doctor's actions could be considered careless, there is no wrong upon which a duty of care could be established. Thus, in the context of the factual matrix of *ABC*, the High Court judge was content to strike the case out on the basis that there was no reasonably arguable duty of care.[12] Leave has been granted to appeal.

While the courts might be able to maintain the position that there is no reasonably arguable duty of care such that the claim is bound to fail where there is no established wrong *or* harm, they may not be able to sustain this clear-cut position in the face of an established legal wrong, and/or an outcome which the law is prepared to recognize as harmful. This is important in the context of a frustrated reproductive choice, where English law has developed from a position of refusing to recognize harm in *McFarlane v. Tayside Health Board*,[13] to recognizing a broad conception of harm only three years later in *Rees v. Darlington Memorial Hospital NHS Trust*.[14]

Non-disclosure of genetic information: Developing perceptions of legally recognized harm

In *ABC*, the defendants were prepared to proceed on the basis that injury to the claimant would have been reasonably foreseeable if the defendant failed to inform her that her father had Huntington's disease.[15] The upshot of this was that the judge did not address the issue of harm, focussing instead on whether a failure to inform a patient's relative of genetic risks was a wrong in respect of which doctors[16] owed a legal duty. However, the decision to concede harm without discussing the point is precarious because the recognition of the birth of a child as legal harm conflicts with sixteen years of case law.

In *McFarlane*, the House of Lords acknowledged that Mrs McFarlane's pregnancy was a direct and foreseeable consequence of the doctor's carelessness in giving negligent information that Mr McFarlane had been rendered infertile after a vasectomy. Thus it seems that they perceived a wrong which had a direct causal link to the birth of the child. However, the House allowed the hospital to escape the consequences of that wrong on

11. The importance of the mother's and the daughter's risk is discussed below.
12. *ABC*, para 31.
13. *McFarlane v. Tayside Health Board* [2000] 2 AC 59.
14. *Rees v. Darlington Memorial Hospital NHS Trust* [2003] UKHL 52.
15. *ABC*, para 11.
16. Nicol J. restricted his judgment to doctors rather than health professionals generally.

the basis that the costs associated with the birth of a child were not actionable harm.[17] This supports the idealistic view that there is a duty not to be careless irrespective of the outcome of that carelessness, although remedies are based on outcomes so the recognition of a wrong alone will not attract a remedy. However, in 'wrongful birth', the existence of a wrong without recognition of harm appears to have led to development in the notion of legal harm.

In *McFarlane*, the House approached the question of the content of the doctor's duty from the perspective of distributive justice.[18] The notion of the tort of negligence as a mechanism for distributing burdens in a way which is fair or optimal for society is often contrasted with the concept of corrective justice, which reflects the idea that liability should rectify the injustice inflicted on one person by another.[19] The latter is arguably more conceptually straightforward because the former is often underpinned by diverse theoretical perspectives regarding fair and optimal resource allocation for society. Although some legal scholars adopt theoretical approaches to distributive justice,[20] in the wrongful birth cases the English courts have adopted an intuitive approach to determining what might achieve distributive justice. Lord Steyn felt that the question of whether the harm should be legally actionable could be decided by asking the commuter on the London Underground whether the parents of an unplanned but healthy child should be able to sue the doctor or hospital for the costs of bringing up the child.[21] In his view, an 'overwhelming number of ordinary men and women would answer this question with an emphatic "No"' based on their views as to what is 'morally acceptable and what is not'.[22] This led the Lords to conclude that the birth of a healthy child is generally viewed as 'a good and valuable thing' and, therefore, not legally actionable harm.[23]

The refusal to recognize that the birth of a child could constitute harm led to two variants of *McFarlane*. In *Parkinson v. Seacroft University Hospital NHS Trust*[24] a mother sought to recover the costs of raising her son who was born following a negligent sterilization. Incidentally, the child had a disability. Bound by the decision in *McFarlane*, the Court of Appeal refused to award the ordinary costs of raising the child. However, it was prepared to award the extra expenses associated with the child's disability. Like the House of Lords in *McFarlane*, the Court of Appeal approached the issue of whether the mother had sustained actionable damage from the perspective of

17. Prior to *McFarlane* the courts had recognized that the costs of raising a child were recoverable where they were a direct consequence of a wrongfully caused birth. See, for example, *Emeh v. Kensington and Westminster Area Health Authority* [1985].
18. *McFarlane*, Lord Steyn 82.
19. E. Weinrib, 'Corrective Justice in a Nutshell', *The University of Toronto Law Journal* 52 (2002), pp. 349–356.
20. P. Cane, 'Distributive Justice and Tort Law', *New Zealand Law Review* 4 (2001), pp. 401–420.
21. *McFarlane* Lord Steyn 82.
22. *McFarlane* Lord Steyn 82.
23. *McFarlane* Lord Steyn 82.
24. *Parkinson v. Seacroft University Hospital NHS Trust* [2001] EWCA Civ. 530.

distributive justice.[25] Although both Brooke LJ and Hale LJ accepted the *McFarlane* position that the mother could not claim the ordinary costs of child rearing, they were not prepared to conclude that the mother of a disabled child should recover nothing. Lady Hale was uneasy about the *McFarlane* decision to deny what would on normal legal principles be recoverable.[26] She said:

> Whatever the commuter on the Underground might think of the claim for Catherine McFarlane, it might reasonably be thought that he or she would not consider it unfair, unjust or disproportionate that the person who had undertaken to prevent conception, pregnancy and birth and negligently failed to do so were held responsible for the extra costs of caring for and bringing up a disabled child.[27]

Thus they were unwilling to maintain a position which denied any recovery in the face of what they considered to be a clear legal wrong. On this basis, the court was prepared to make an award relating to the disability even though it was clear that the disability was not caused by the negligence. Thus it seems that the desire to do practical justice for the wronged claimant in *Parkinson* persuaded the Court of Appeal to make an immaterial distinction to House of Lords precedent in order to recognize harm. *Parkinson* is not the only claim where the court's desire to provide a remedy for the wronged claimant led it to recognize an outcome, which is not materially different to the outcome in *McFarlane*, as harmful.

In *Rees* Karina Rees underwent sterilization because she felt that her severe visual impairment would make it difficult for her to care for a child. She conceived a healthy son after the sterilization was performed negligently and claimed the costs of raising him. A seven-member House of Lords refused to overturn *McFarlane*, maintaining that parenting a healthy child was a valuable experience which the law should not recognize as harm. However, similar to *Parkinson*, their Lordships were uneasy about leaving the claimant without a remedy in the face of what they perceived to be a clear legal wrong. Lord Bingham questioned 'the fairness of a rule which denies the victim of a legal wrong any recompense'.[28] Along with the remaining majority, he felt that there should be some recovery to 'mark the injury and loss'[29] in all such cases. On this analysis, the healthy mother of a healthy child would also be entitled to a remedy. Lord Millett agreed that the mother should be entitled to a remedy. However, he took a different approach to the basis of an award. Rather than a means of marking 'the injury and loss', according to Lord Millett the award, which took the form of a conventional sum, was to recognize the wrong done.[30] Lord Millett spoke in the language of rights and held that Ms Rees had been denied an aspect of human dignity, an important human right which he felt should

25. Throughout the judgments of Brooke L.J. and Hale L.J.
26. *Parkinson*, para 79.
27. *Parkinson*, para 95.
28. *Rees* Lord Bingham, para 8.
29. *Rees* Lord Bingham, para 8.
30. *Rees* Lord Millett, para 123, Lord Bingham, para 8, Lord Nicholls, para 17, and Lord Scott, para 148.

be protected by law.[31] This approach could be seen as reflecting the idealistic perspective that there can be a stand-alone duty not to be careless irrespective of the outcome of the carelessness.

Like these wrongful birth cases, the harm in *ABC* was presented as being the birth of a child. Although, conversely to existing precedent, in *ABC* the defendants were prepared to concede harm. However, if the concept of harm is argued in the Court of Appeal in *ABC*, this is likely to lead to a consideration of the wrongful birth litigation which demonstrates that the question of whether the birth of a child is encompassed by the duty of care present in sterilization procedures is still a matter of debate. The essence of the mother's claim in *ABC* is that the birth of her daughter is a harmful outcome because, if she had known of the risk, she would have undergone testing to see whether she (the mother) had the Huntington's gene and, if she had, she would have terminated the pregnancy. It is not entirely clear whether her reasons for doing this would have been because she would develop Huntington's or because of the risk that the child would develop Huntington's.

Let us assume first that her argument is that the birth of her daughter is harmful because of the costs associated with the impending possible onset of Huntington's disease in her daughter. This type of argument might find most support from the Court of Appeal decision in *Parkinson*. However arguing that the birth of the claimant's child is harmful because the child has a disability is problematic where the child does not in fact have a disability. The claimant's daughter is, as far as we know, currently perfectly healthy. She has a 50% chance of suffering from Huntington's disease in the future because she has a 50% chance of possessing the gene that we now know her mother possesses. This situation can be distinguished from the case of *Parkinson* (where the child actually suffered from an existing disability) in two key ways. First, it is not clear whether the claimant's daughter will ever develop Huntington's because she has a 50% chance of not possessing Huntington's gene. If the harm in this case depends upon the child's Huntington's susceptibility, it seems to make sense that she can only recover if she proves to have that susceptibility. However, there is a very strong professional ethic against testing in childhood for adult onset genetic disorders.[32] Furthermore there is no evidence that the claimant wants her daughter to be tested or, for that matter, that any professional is willing to test her.

The latency of Huntington's disease presents further problems for the mother's claim for damages based on the additional expenses which she will incur if her daughter does have Huntington's gene. Although Huntington's disease has a wide variation in onset age, the average age at onset is 40 years,[33] which means that the claimant's daughter is unlikely to incur any additional expenses in childhood even if she does have Huntington's gene. If her daughter does have the gene, she will only manifest this in adulthood. Thus any expenses associated with it will be incurred directly to the adult daughter, at

31. *Rees* Lord Millett, para 123.
32. For the importance of this in the context of a legal challenge see *Re Y and Z (Minors)* [2013] EWHC 953 (Fam).
33. R.H. Myers, 'Huntington's Disease Genetics', *NeuroRX* 1 (2004), pp. 255–262.

which point there is no legal parental responsibility to care for, or finance one's offspring.

Thus the claimant in *ABC* is likely to experience significant difficulty in aligning her claim to recover additional expenses involved in raising her child with the claim in *Parkinson*. She might have a stronger claim that she has suffered harm if she argues that the additional costs she will incur relate to her desire not to have a child, as opposed to her daughter's potential disability. The Particulars of Claim state:

> She pleads that if she had been informed of her father's condition, she would have undergone a test to see if she had it as well. Once that showed positive, she would have terminated her pregnancy.[34]

There is no suggestion that the claimant would have undergone prenatal testing to determine her daughter's Huntington's gene status, which suggests that the knowledge that she herself would develop Huntington's was instrumental to her choice to terminate. From this perspective, the claim is more closely aligned with *Rees* than *Parkinson*.

The award of the conventional sum in *Rees* was not explicitly related to the fact that the mother was disabled. However, even if the mother's disability is deemed to be a material fact in a future judicial assessment of *Rees*, the claimant in *ABC* has a strong claim to a conventional sum in any event because she suffers from Huntington's disease and it is this factor, had she known it, that would have affected her desire to have a child.

Although Lord Millett presented an idealistic perspective of the conventional sum as a recognition of the wrong done in carelessly failing to sterilize Ms Rees, a number of commentators adopt a different interpretation of *Rees*, reflecting a more cynical view of the duty of care. They argue that the conventional sum *is* a recognition of a new form of harm as opposed to the simple recognition of a wrong.[35] Lord Scott spoke clearly in the language of compensation and argued that the purpose of the conventional sum was to 'compensate the respondent for being deprived of the benefit that she was entitled to expect'.[36] Although he said the conventional sum was a recognition of wrong, Lord Millett also seemed to recognize that some further adverse outcome should result from that wrong. In *Rees* Lord Millett effectively acknowledged that there was a harm in the form of an interference with the interest in autonomy which was occasioned by disrespecting the 'right to limit the size of [one's] family'.[37] If harm in the form of

34. *ABC*, para 2.
35. D. Nolan, 'New Forms of Damage in Negligence', *Modern Law Review* 70 (2007), pp. 59–88; N. Priaulx, *The Harm Paradox: Tort Law and the Unwanted Child in an Era of Choice* (Oxford: Routledge-Cavendish, 2007); N. Priaulx, 'Joy to the World! A (Healthy) Child is Born! Reconceptualizing "Harm" in Wrongful Conception', *Social and Legal Studies* 13 (2004), pp. 5–26 and V. Chico, *Genomic Negligence: An Interest in Autonomy as the Basis for Novel Negligence Claims Generated by Genetic Technology* (London: Routledge Cavendish 2011).
36. *Rees* Lord Scott, para 356.
37. *Rees* Lord Millett, para 123.

interference with autonomy is capable of being recognized in the tort of negligence,[38] it follows that outcomes which result from the failure to offer genetic choice could be considered to be legal harm.[39] However, it is unlikely that the courts will be prepared to recognize frustrated choice as a harm in and of itself. They are likely to require the frustrated choice to lead to some further tangible outcome.[40] Indeed, although *Rees* can be interpreted as providing a remedy for the interference with autonomy, the reasoning suggests that the House of Lords required the interference with that interest to lead to more tangible consequences which the law could conceive to be harmful. Thus it might be argued that in *Rees* it was crucial to Ms Rees success that she had had a child. Given that the claimant in *ABC* has given birth to the child, this outcome could be seen as an interference with her interest in autonomy as she would have elected not to have the child if the information which existed, which would have allowed her to make this choice, had been disclosed to her.

Government figures suggest that the approach to wrongful birth claims out of court *does* recognize that the birth of an unwanted child can be considered harmful. The National Health Service has paid out more than £95 million since 2003[41] on 164 successful claims for damages from parents wanting compensation for the birth of a child.[42] Thus although the leading UK legal authority on wrongful birth rules that the birth of a child is not in itself legal harm,[43] practice has evolved such that this legal doctrine does not seem to reflect the practical approach to the recognition of legal harm.

The type of harm alleged in *ABC* is not the only potential adverse outcome that might follow a failure to disclose a genetic risk. Indeed, in the legal sense at least, *ABC* represents the thin end of the harm wedge. The failure to disclose genetic information may more commonly lead to the manifestation of a preventable medical condition, than the birth of an unwanted child, and the manifestation of a preventable medical condition *is* an outcome which the tort of negligence can readily recognize as harm.[44] Consider the claim where a patient's familial adenomatous polyposis (FAP) diagnosis is not communicated to her child who has a 50% chance of possessing the FAP gene which is almost

38. Other cases that suggest that this might be a possibility are *Chester v. Afshar* [2004] UKHL 41 and *Yearworth and Others v. North Bristol NHS Trust* [2009] EWCA Civ 37. See also the author's previous work on recognising harm in the form of interference with autonomy in the tort of negligence Chico, '*Genomic Negligence*'.
39. See my previous work on this issue Chico, '*Genomic Negligence*'.
40. See my previous work on the interest in autonomy as the basis for novel actions in the tort of negligence. Chico, '*Genomic Negligence*'.
41. When *Rees* was heard.
42. Available at: http://www.theyworkforyou.com/wrans/?id=2014-09-09.208750.h&s=speaker%3A24927#g208750.q0) (accessed 18 April 2016). Available at: http://www.conservativewoman.co.uk/philippa-taylor-compensation-culture-gone-mad-cash-strapped-nhs-shells-millions-unwanted-healthy-babies/ (accessed 22 March 2016).
43. The House of Lords decision in *McFarlane* which has been upheld in *Parkinson* and *Rees.*
44. In *Gregg v. Scott* [2005] UKHL 2 if the delay in diagnosis had on the balance of probabilities prevented the cancer from being cured, the case would not have turned on whether the advanced cancer amounted to a personal injury.

100% penetrant,[45] and where the risk of the manifestation of bowel cancer can be prevented or minimized by screening, surveillance or surgery.[46] Where a doctor fails to provide this opportunity to have treatment which will almost certainly avoid physical harm, the case will not turn on whether the loss amounts to legally recognizable harm and correspondingly whether there is a duty not to be careless where that carelessness does not cause harm. However, because it is currently not considered to be careless for doctors not to disclose genetic information to patients' families, any harmful outcome, not matter how clear it is, will not receive a remedy because the lack of a legal wrong is fatal to the imposition of a duty of care.

However, the wrongful birth cases appear to demonstrate that the courts are struggling to refuse to recognize harm where a careless action, which is clearly recognized as a legal wrong, has led to the very outcome that the wrong was supposed to prevent. This wrongful birth jurisprudence has developed on the basis of distributive justice, as determined by how the courts assume ordinary people will feel about providing a remedy based on the birth of a child. Unsurprisingly, the courts are unable to portray certainty in their thinking about how ordinary people will feel about awarding damages for the birth of a wrongfully born child.[47] Thus we are left with judicial intuitions of what they think the public will accept. Although the House of Lords was firm in its view that people would think the birth of a child should not constitute actionable harm in *McFarlane*, the Court of Appeal in *Parkinson* and a differently constituted House of Lords in *Rees*, thought that ordinary people *would* recognize a harm in a birth that the defendant had undertaken to prevent. Thus it might be argued that the existence of a legal wrong, and the courts' perception of corresponding sympathy that is likely to be felt for the victim of a legal wrong, influenced the expansion of the boundaries of actionable harm in the context of wrongful birth.

The legal recognition of interference with the interest in autonomy as harmful in *Rees* will allow the claimant in *ABC* to demonstrate harm if this point is addressed in the Court of Appeal. However, the crux of the judgment in the High Court was that, irrespective of the outcome, the non-disclosure did not constitute a wrong. Although there is ambiguity concerning whether a wrong that does not lead to a harmful outcome can be the subject of a duty of care,[48] it is clear that the converse of a harm without a wrong is not sufficient to establish liability. Indeed, relying heavily on the judgment in *ABC*, in *Smith v.*

45. Meaning that a person with the relevant mutation in this gene is almost certain to develop colorectal cancer before they are 40. M. William Audeh, 'Genetic and Environmental Factors in Cancer Pathogenesis', in H. Silberman and A.W. Silberman (eds) *Principles and Practice of Surgical Oncology* (London: Lippincott, Williams & Wilkins, 2010), pp. 29–50.
46. S. Winawer, R. Fletcher, D. Rex, et al., 'Colorectal Cancer Screening and Surveillance: Clinical Guidelines and Rationale—Update Based on New Evidence', *Gastroenterology* 124 (2003), pp. 544–560.
47. There are many reasons why the judiciary might find reflection of popular views difficult. The issue may be one on which pubic views are scattered and/or ambivalent, especially where there are plausible arguments for and against each approach as in the 'wrongful birth' cases. Furthermore the judiciary is not often in a practical position to know with clarity what public opinion is because empirical evidence is lacking.
48. See the earlier discussion of cynical and idealistic approaches to duties of care.

University of Leicester NHS Trust,[49] the High Court recently struck out a claim where a personal injury was suffered because of an omission in the treatment of another which lead to a failure to disclose information to the injured party. Despite striking the claim out, the court recognized that injury was reasonably foreseeable[50] but they declined to provide a remedy for that personal injury on the basis that it did not result from a legal wrong. However, as the argument here demonstrates, the courts have developed legal conceptions of actionable harm based on a perception that ordinary people will be disposed to recognize an outcome as harmful where it results from a legal wrong. Thus might the courts similarly develop legal conceptions of what is wrongful where an act or omission results in legally recognized harm? If a claim concerning a non-disclosure of genetic information does lead to harmful outcomes, whether that be the birth of a child as in *ABC*, or a clearer perception of harm in the form of the manifestation of an avoidable genetic condition,[51] will the sympathy that people feel for those who suffer harm influence them to perceive the action which caused the harm as wrongful? In the wrongful birth context, reliance on perceptions of public opinion led to the development of new conceptions of legal harm. If we consider non-disclosure of genetic information to a relative who then suffers a harm which could easily receive legal recognition,[52] judicial perceptions of sympathetic public opinion might influence the courts to expand categories of wrong accordingly.

As with the question of whether people who seek sterilization should be seen to have suffered harm when carelessness in that sterilization leads to the birth of a child, the issue of whether doctors should have a duty to warn patients' relatives of genetic risks is likely to be an issue which, on the face of it, could be subject to conflicting public opinions, because it impinges on a number of different competing claims to the public interest. It has long been recognized in English law that the public interest is served by maintaining confidence in medical relationships which will promote candour.[53] Competing public interests have only overridden this interest where there is a clear risk of serious physical harm to the public.[54] However, it is becoming increasingly obvious that this traditional view of medical relationships where individualism and confidentiality set the parameters does not reflect public opinion in the context of familial sharing of genetic information concerning highly relevant and actionable genetic risks. Indeed, if relying on public opinion is relevant in developing legal rules,[55] non-disclosure of genetic information

49. *Smith v. University of Leicester NHS Trust* [2016] EWHC 817 (QB).
50. *Smith*, para 20.
51. As in the familial adenomatous polyposis example offered above.
52. Perhaps as in the example of the manifestation of a readily treatable genetic condition.
53. *X v. Y* [1988] 2 All ER 648.
54. *W v. Egdell* [1989] EWCA Civ 13. There is a developed US jurisprudence on the duty to warn of many different risks. However this case law has been subject of numerous previous articles and is therefore not discussed here. See in particular *Tarasoff v. Regents of the University of California* 17 Cal. 3d 425.
55. As it was in the 'wrongful birth' litigation. Although there are scholars who doubt that this is an appropriate mechanism for developing the law. See, for example, A. Beever *Rediscovering the Law of Negligence* (Oxford: Hart Publishing, 2007).

is an area where reflecting public opinion is increasingly possible because of the significant and growing evidence of public views. However, in *ABC*, this empirical evidence did not influence the judge's discussion of the implications of recognizing a duty to disclose genetic risks.

Non-disclosure of genetic information: Developing perceptions of legally recognized wrongs

According to Nicol J., the failure to disclose the genetic information in *ABC* amounted to an omission.[56] In the absence of a principle, such as reliance[57] or an assumption of responsibility,[58] which might import a special relationship, he felt that the defendant had done nothing wrong in failing to disclose the genetic information to the claimant. Thus the claim was struck out on the basis that there was no reasonably arguable duty of care.[59] This decision was heavily influenced by general concerns about the wider implications that counsel for the defendants argued would follow if doctors owed a duty to disclose genetic information to patients' relatives. In analysing the appropriateness of these policy concerns in the context of imposing a duty of care for non-disclosure of genetic risk generally, this article will assume recognized legal harm,[60] such that any duty of care would correspond with the cynical perspective on the existence of duties.

The nine policy issues cited by Nicol J. focused on the position that doctors would be in if they owed potentially conflicting duties to patients to maintain confidence, and to patients' relatives to prevent harm through disclosure of information.[61] Essentially, the nine policy issues boiled down to three overarching concerns; first, that a duty could impact on the doctor–patient relationship, thereby undermining trust and confidence. Second, that doctors would have no way of knowing whether or not people wanted to be informed, and this situation might expose them to additional liability. Cumulatively, these concerns led to a third concern that a duty would place burdensome responsibilities on doctors which would incur time and resources distracting them from treating patients.[62] However, it might be argued that this analysis is largely based on assumptions. First, the judge assumed that the issue of genetic disclosure was only relevant in the doctor–patient context.[63] Following this, he made a number of assumptions about how doctors, patients and their relatives feel about the receipt of, and sharing of, genetic information which led him to over-emphasize the importance of protecting doctors from a duty of care. This article considers the judge's policy concerns in light of empirical

56. *ABC*, para 28.
57. *ABC*, para 28
58. *ABC*, para 28.
59. *ABC*, para 31.
60. Whether that is because the birth of an unwanted child is clearly recognized as harmful, or because the harm is the manifestation of a preventable genetic condition; as presented in the familial adenomatous polyposis example above.
61. *ABC*, para 13.
62. *ABC*, para 13.
63. Nicol J. considered all nine policy reasons from the perspective of doctors only.

evidence of attitudes towards receiving and sharing genetic information which presents a more balanced view of the concerns that might be raised in the context of a duty to disclose genetic information.

The implications for the doctor–patient relationship

The situations where genetic information that is relevant to people's health choices might arise are broad and complex. Genetic testing is available in a variety of different commercial, research and non-commercial settings. The refusal to recognize a duty of care to relatives in *ABC* was based exclusively on the impact that the imposition of a duty might have on the nature of the relationship between the doctor and the tested patient.[64]

Nicol J.'s consideration of the issue exclusively from the perspective of doctors overlooks the fact that people other than doctors might obtain genetic information that could be important to the health of another. There are many other health professionals who may come into receipt of genetic information in the same way as doctors, which could be shared with the families of their patients not least, genetic counsellors and nurses. The exclusive focus on doctors in *ABC* may leave other healthcare professionals confused about whether the same legal rules apply to them. Although other health professionals may come to learn of genetic information in the same way as doctors, they might spend more time with patients and families than doctors and might not feel that a duty of care would impact on their position in the same way as the court in *ABC* thought it might impact upon a doctor's position.[65]

As whole genome sequencing becomes more common in clinical, research and commercial contexts, many different and diverse professionals may receive additional information about a patient's or participant's genetic risks which may or may not have been predicted and provided for by way of consent. Indeed, the issue of what duties health professionals might owe to their patients in the context of projects like the 100,000 Genomes Project is currently under debate.[66] In some ways this represents a different situation to disclosing information to relatives because the notion of consent might operate. Nevertheless, it is similarly a situation where there is no legal authority determining whether the would-be disclosee owes a duty of care. In the 100,000 Genomes Project, people are asked to consent to receive information about a small list of additional findings.[67] Where a consent to disclosure of particular information is gained, it might be argued that an assumption of responsibility follows the act of gaining consent to disclosure, such that if the relevant genetic information is present, a subsequent non-disclosure of this information is a prima facie wrong, for which it is difficult to deny a duty of care. However, not all situations where additional genetic risk information arises

64. *ABC*, para 13.
65. The impact on doctors predicted in *ABC* is based on the court's view of potential impact, as opposed to the view of the medical profession.
66. See for example my previous work on this issue V. Chico, 'Requiring Genetic Knowledge: A Principled Case for Support', *Legal Studies* 35 (2015), pp. 532–550.
67. Available at: http://www.genomicsengland.co.uk/taking-part/patient-information-sheets-and-consent-forms/ (accessed 18 March 2016).

about a patient will be covered by consent. The list of conditions whereby consent to disclosure can be given are drawn up by clinicians because of the characteristics of these conditions, mainly that they are actionable. On this model, these mutations are then actively looked for. True incidental findings might not be planned for or consented to. This wider view of circumstances where disclosure of genetic information might be relevant and the professionals who might have responsibilities in relation to this disclosure, calls into question the singular focus on the impact of doctor–patient relationship in *ABC*.

The conflict with the duty to maintain confidence

Where patient information cannot provide a benefit to others, maintaining confidence is likely to be of significant import to patients. However, there is a growing discourse addressing the role of confidentiality in the context of information which could be beneficial to the health of others specifically or generally.[68] Indeed there are a number of ways that otherwise confidential patient data can be used in a manner which does not breach confidence.[69] The competing arguments portraying both public and private interests at stake in maintaining and breaching confidence have been well rehearsed elsewhere.[70] This article does not seek to repeat these arguments. However, much of this literature approaches the concept of confidence from a general perspective which assumes a conflict between confidence and the duty to warn. We should not generally assume this conflict in the circumstances of familial sharing of actionable genetic information because empirical evidence suggests that it rarely exists. Indeed, while it is clear that people do value the confidentiality of their health data, it seems that the key concern for people in terms of their health data is not whether their information is kept a secret from the rest of their family. Here there seems generally to be a culture of sharing that is not well reflected in the theoretical literature addressing the relative interests in

68. See for example the Information Governance Review March 2013 Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf (accessed 22 March 2016); J. Persson, 'Care.Data: The Economic Value of Data Versus the Public Interest?', Available at: https://www.statslife.org.uk/opinion/2282-care-data-the-economic-value-of-data-versus-the-public-interest (accessed 22 March 2016); C.F. Wright, E. Hurles and H.V. Firth 'Principle of Proportionality in Genomic Data Sharing', *Nature Reviews Genetics* 17 (2016) pp. 1–2; A. Davey, A. Newson and P.O. Leary, 'Communication of Genetic Information Within Families: The Case for Familial Comity', *Bioethical Inquiry* 3 (2006), pp. 161–167; H. Widdows, 'Between the Individual and the Community: The Impact of Genetics on Ethical Models', *New Genetics and Society* 28 (2009), pp. 173–188; C. Foster, J. Herring and M. Boyd, 'Testing the Limits of the 'Joint Account' Model of Genetic Information: A Legal Thought Experiment,' *Journal of Medical Ethics* 41 (2015), pp. 379–382.

69. For example, consent, public interest and statutory grounds provide for use of otherwise confidential patient data. In particular see The Health Service (Control of Patient Information) Regulations 2002 and the work of the Confidentiality Advisory Group.

70. See in particular G. Laurie, *Genetic Privacy: A Challenge to Medico-legal Norms.* (Cambridge: Cambridge University Press, 2002).

maintaining and breaching confidence. It might be argued that this culture of sharing ought to diminish the concerns associated with imposing conflicting duties on doctors[71] because, given the culture of sharing, such a conflict rarely occurs.

Recent empirical research shows that most people do not place significant importance on confidentiality where information might allow relatives to avoid a genetic condition.[72] This research demonstrates that people overwhelmingly want relevant genetic information, believe their interest in knowing this information should override their relative's right to keep it confidential and would forgo their own confidentiality so that their relatives could have this information.[73] Thus the situation where health professionals have information that is not known by the relative, where they feel it would be appropriate to disclose, where that disclosure is not supported by the patient, is not likely to occur particularly often. If conflict between the duty to disclose and the duty to maintain confidence will be a rare occurrence, this diminishes the relevance of this concern and therefore its justification for the argument that a duty to disclose should not be imposed. Indeed the norm in the context of the duty to disclose will be that the doctor explains the need to inform relatives to the patient, and the patient discloses the information to their relatives with support from the multidisciplinary team.

Nevertheless, a minority will refuse to disclose information to their relatives. It is in this context that Nicol J.'s concerns about the doctor–patient relationship crystallize. His concern is that conflicting duties would 'undermine the trust which is so important to the doctor/patient relationship'.[74] Again the importance of trust in doctor–patient relationships and the role that the duty to maintain confidence plays in establishing that trust has been well considered elsewhere.[75] However, it might be argued that attributing utmost importance to the concept of confidentiality even where maintaining confidence prevents another's ability to avoid harm represents a one-dimensional interpretation of trust in medical relationships which might not be appropriate in the context of genetic medicine. Most medical treatment relationships involve more than just the patient and one doctor. Doctors work in multidisciplinary teams and people exist in relationships, some of which involve a high degree of dependence. Increasingly, the model of patient care adopted in genetic medicine reflects this relational focus and treats families as opposed to individual patients.

In modern genetic medical practice, it is not uncommon for geneticists/genetic counsellors to assume a responsibility for the genetic well-being of families. Indeed the Association of Genetic Nurses and Counsellors describes the aims of genetic counselling as:

71. Cited by Nicol J. at para 13.
72. T.J. Heaton and V. Chico, 'Attitudes Towards the Sharing of Genetic Information with at-Risk Relatives: Results of a Quantitative Survey', *Human Genetics* 135 (2016), pp. 109–120.
73. T.J. Heaton and V. Chico, 'Attitudes Towards the Sharing'.
74. *ABC*, para 13.
75. See, for example, G. Laurie, '*Genetic Privacy*' and R. Chadwick, 'Genetic Diagnostic Information and the Duty of Confidentiality', *Medical Law International* 1 (1993), pp. 73–95.

> to help the individual or family understand the information about the genetic condition, appreciate the inheritance pattern and risk of recurrence, understand the options available and make decisions appropriate to their personal and family situation.[76]

The issue of whether to disclose genetic information to a person which might give them the opportunity to make choices which they would not otherwise be able to make, has long been an element of the genetic professions.[77] However, any professional assumption of responsibility has not led to a legal duty, rather the traditional legal duty to maintain confidence sets the legal guidance in the context of disclosure of genetic information to relatives. However, the absence of a recognized duty to warn patients' relatives of relevant genetic risk information has led to grievances concerning failures to disclose genetic information that a patient's relative could have acted upon, which have been settled out of court in favour of the relative.[78] In the professional context, this kind of settlement can have a significant impact on practice, influencing the profession to act as if it were subject to a duty which is over and above the duty imposed by the law.[79] Indeed, a recent systematic review and synthesis of empirical research showed that health professionals generally felt some responsibility to patients' relatives to disclose information.[80] This responsibility was most acutely experienced by genetic counsellors and geneticists. Two US studies, one with genetic counsellors[81] and one with clinical geneticists[82] found that 63% (161/257) of genetic counsellors and 69% (143/206) of geneticists, perceived an obligation to disclose. This sense of a responsibility to disclose can also be seen in the theoretical literature where a number of commentators argue for a familial approach where genetic risk information is treated as a familial resource. Gilbar advocates the adoption of a relational perception of autonomy, which, in the context of genetics, takes into account the effect that any decision – whether to disclose or not to disclose – will have on the familial relationship and the dynamics of the particular

76. Available at: http://www.agnc.org.uk/media/689675/careerasageneticcounsellor2.pdf (accessed February 19 2016).
77. See, for example, K. Offit, et al., 'The "Duty to Warn'; B.M. Knoppers, Y. Joly, J. Simard, et al. 'The Emergence of an Ethical Duty to Disclose Genetic Research Results: International Perspectives', *European Journal of Human Genetics* 14 (2006), pp. 1170–1178.
78. Personal communication with a geneticist at The British Society for Genetic Medicine 22–24th September 2014, Arena and Convention Centre, Liverpool.
79. C. Foster and J. Miola, 'Who's in Charge? The Relationship Between Medical Law, Medical Ethics and Medical Morality?', *Medical Law Review* 23 (2015), pp. 505–530.
80. S. Dheensa, A. Fenwick, S. Shkedi-Rafid, et al., 'Health-care Professionals' Responsibility to Patients' Relatives in Genetic Medicine: A Systematic Review and Synthesis of Empirical Research', *Genetics in Medicine* 18 (2016), pp. 290–301.
81. R.B. Dugan, G.L. Wiesner, E.T. Juengst, et al. 'Duty to Warn at-risk Relatives for Genetic Disease: Genetic Counselors' Clinical Experience', *American Journal of Medical Genetics (Sem Med Genet)* 119C (2003), pp. 27–34.
82. M.J. Falk, R.B. Dugan, M.A. O'Riordan, et al. 'Medical Geneticists' Duty to Warn at-risk Relatives for Genetic Disease', *American Journal of Medical Genetics* 120A (2003), pp. 374–380.

family.[83] Parker and Lucassen argue that the familial approach to genetic information is an important aspect of establishing trust in genetics professionals. They propose the 'joint account' model where the question becomes not when to respect confidentiality but what, if anything, would justify excluding others from the joint account.[84] It is assumed that information should be available to all account holders unless there are good reasons to do otherwise. They argue that an advantage of the joint account model is that it is consistent with the nature of practice in clinical genetics. Geneticists work with families. This means that geneticists often come to know and to feel a sense of responsibility for several members of the same family.[85] In this context, Parker and Lucassen do not focus on trust between individual patients and doctors. They present a different perspective of how trust might be construed and undermined:

> when relatives who were not informed about their risk develop symptoms or become aware of their family history, and that this was withheld from them, they may lose trust in their doctors. More generally, if it becomes widely known that information of this kind is being routinely withheld, at the request of affected family members, it may lead to a more widespread crisis of trust in the clinical genetics service and possibly legal action.[86]

This attitude of sharing genetic information to gain the trust of families is also reflected in professional guidance,[87] demonstrating that the practice of genetic medicine adopts a more progressive familial interpretation of trust as opposed to the traditional individual patient interpretation which is at the heart of approaches which favour confidentiality. From the perspective of modern genetic practice, it might be argued that the legal approach of championing confidence in the face of avoidable harm reflects outdated thinking which does not follow the current professional approach. The wider view of sharing as crucial to trust, rather than inimical to it, will allow information to be shared in a way that enables a clearer and better approach to individual disease, but also furthers knowledge of the genetic condition generally, thereby allowing genetic medicine to fulfil its potential.[88]

---

83. R. Gilbar, 'Communicating Genetic Information in the Family: The Familial Relationship as the Forgotten Factor', *Journal of Medical Ethics* 33 (2007), pp. 390–393.
84. A. Lucassen and M. Parker, 'Genetic Information: A Joint Account?', *British Medical Journal* 329 (2004), pp. 165–167.
85. Lucassen and Parker, 'Genetic Information'.
86. Lucassen and Parker, 'Genetic Information'.
87. Royal College of Physicians, Royal College of Pathologists and British Society for Human Genetics. *Consent and Confidentiality in Clinical Genetic Practice: Guidance on Genetic Testing and Sharing Genetic Information.* 2nd ed. Report of the Joint Committee on Medical Genetics. London: RCP, RCPath, 2011.
88. Many questions concerning whether to disclose genetic information will arise in situations where a geneticist is involved. If Parker and Lucassen's view reflects a more general position, then geneticists and genetic counsellors might not struggle with this duty in a way that the High Court thinks that non-genetically qualified clinicians might. If this is the case, a greater role for genetic counsellors in mainstream medicine might be appropriate.

Genetic professionals' desire to share genetic information in families is reflected in the attitudes of patients and the public. Empirical evidence demonstrates that people are generally happy to forgo their own confidentiality in the context of genetic findings relevant to family members. Recent empirical investigation of people's views on sharing genetic information in families provided estimates of the views of the British public; in the case of a fatal and preventable disease, the study found that 93% of the British public would be willing to forgo their confidentiality if their genetic information could benefit family members,[89] with 72% of people feeling strongly that they would be willing to forgo confidence.[90]

Interestingly, the confidential information in *ABC* would have become known to the claimant in the near future because her father was suffering from the symptoms of the condition which he would not be able to conceal from her indefinitely. Information which is in the public domain does not incur a duty of confidence. Where the information will shortly, inevitably be in the public domain, but this is after the harm which the information could prevent has occurred, as in the birth of the child in *ABC*, should the balancing of relevant interests represent the temporary ability of the information to remain confidential? Furthermore, the father in *ABC* specifically asked for his daughter not to be told because she might 'have an abortion'.[91] The interest in confidence protects the individual, by maintaining the secrecy of facts about them that they do not want others to know, it is not a means of controlling the actions of third parties. Of course, a person does not need to give their reasons for wanting to keep their information confidential. However, we might want to question giving ultimate respect to confidentiality where the secrecy of the information which is the subject of the confidence is temporary and short-lived, and the reason for wanting to maintain confidence in any event is not to protect secrecy per se, but to prevent another from averting the harm that will occur if the information is kept secret until it emerges naturally. As it was, the father relied on his interest in confidentiality to prevent his daughter from accessing her right to abortion in a jurisdiction where women have a right to abortion which no other individual can interfere with.[92]

The desire not to know genetic information

There is significant literature, and support in international human rights documents, for the right not to know medical information about oneself.[93] This is not a legal right but it

89. Heaton and Chico, 'Attitudes Towards the Sharing'.
90. Heaton and Chico, 'Attitudes Towards the Sharing'.
91. *ABC*, para 5.
92. Assuming they meet the Abortion Act 1967 criteria which would not have been difficult for the claimant in *ABC*. Indeed parents of minors have no right to interfere with their child's right to have an abortion *R (on the application of Axon) v. Secretary of State for Health* [2006] EWHC 37 (Admin).
93. See for example R. Chadwick, M. Levitt and D. Shickle (eds) *The Right to Know and the Right Not to Know Genetic Privacy and Responsibility* (Cambridge: Cambridge University Press, 2014); R. Andorno, 'The Right Not to Know: An Autonomy Based Approach',

cannot be ignored by those proving healthcare. Historically, respecting the interest in not knowing has been presented as problematic on the basis that there will be little clarity regarding whether this is a right people want to exercise or not.[94] The crux of the problem is that we cannot find out whether or not people want to know by asking them because this will make known the existence of, and essential quality of, the information. The upshot of this kind of argument seems to be that there should be a default position of non-disclosure on the basis that disclosure might offend the right not to know. Indeed this is the position reflected by Nicol J. in his account of the policy reasons for declining to impose a duty to warn. However again, it might be argued that the initial theoretical position presenting the right not to know as problematic in the context of providing warnings is not demonstrated in the emerging empirical evidence. Recent research demonstrates that people have a very strong desire to know about actionable genetic risks when that information arises from a test on their relative.[95] An overwhelming number of people (91%)[96] want to know information about their genetic risk that arises as a result of a test on a relative where it relates to a fatal and preventable disease. Furthermore 63% of those people felt 'very strongly' that they would like to be contacted.[97]

People feel particularly strongly that they should be informed of genetic information which could lead to a choice to minimize or prevent a genetic condition,[98] indicating that preventability is instrumental in people's desire to know genetic information. This leads to a perception of harm where there is a manifestation of a genetic condition which could have been prevented or minimized if the information had been disclosed. Furthermore as discussed earlier, this kind of harm, that is, the manifestation of a preventable genetic condition, is one which, theoretically the tort of negligence, is eminently able to recognize.

Thus in the event of preventable genetic disease, people overwhelmingly *do* want to know relevant information and there is little desire to exercise a right not to know. This widespread and general desire to have actionable information, coupled with a perception that harm has occurred when the choice which that information would have presented is

---

Journal of Medical Ethics 30 (2004), pp. 435–439; J. Raikka, 'Freedom and a Right (Not) to Know', *Bioethics* 12 (1998), pp. 49–63; R. Chadwick, M. Levitt and D. Shickle (eds) *The Right to Know and the Right Not to Know* (Aldershot: Avebury, 1997); Article 10(2) of the Council of Europe Convention on Human Rights and Biomedicine and Article 5c of the UNESCO Universal Declaration on the Human Genome and Human Rights.

94. See for example Chadwick et al. '*The Right to Know'*.
95. Heaton and Chico, 'Attitudes Towards Sharing'. See also Dheensa et al., 'Health-care Professionals' Responsibility to Patients' Relatives in Genetic Medicine: A Systematic Review and Synthesis of Empirical Research', *Genetics in Medicine* 18 (2016), pp. 290–301.
96. 91% in this study where the sample was reweighted to reflect the demographics of the British (i.e. English, Scottish and Welsh) population, to provide preliminary estimates on the proportion of the public who do, and do not, favour disclosure.
97. Heaton and Chico, 'Attitudes Towards the Sharing'.
98. S. Dheensa et al., 'Health-care Professionals'.

frustrated, may influence the view that people have suffered a wrong when they do not receive information that they could act on to avoid deleterious outcomes. Nicol J. does not distinguish between actionable and non-actionable genetic information when describing the policy reasons which led him to the conclusion that it would not be just, fair and reasonable to impose a duty to disclose information to relatives. However, it might be argued that any duty could justifiably be limited to a duty to disclose information which concerns a preventable or treatable genetic condition, where we know that a desire not to know is very rare and, therefore, should not be a major concern impeding disclosure. It is in the context of untreatable disease that uncertainty and doubt about the desire to know kicks in.[99] However, untreatable genetic risk could be the subject of a default position of respecting the interest in not knowing. Here there is a stronger argument that some people will want to exercise a right not to know.[100] Furthermore in the legal context it makes much less sense to impose a duty regarding conditions which are not preventable because if the manifestation of the condition represents the harm, and there was nothing the relative could have done in any event to prevent that manifestation, the health professional will not have caused any harm by failing to disclose the information about the genetic risk.

Nicol J. went as far as to suggest that people might suffer psychiatric harm if they receive genetic risk information.[101] However, if we focus on actionable information, as was the case in *ABC,* we know that most people express a desire to know such information, making such an adverse psychological reaction to disclosure unlikely. Indeed, they are arguably more likely to suffer an adverse psychological reaction if they find out that information existed that would have allowed them to prevent or minimize the manifestation of a genetic condition after that condition has manifested and it is too late. Further even if a person feels aggrieved in the first instance when they receive the information, this may not be a lasting emotion. Especially in avoidable disease where people can focus on minimizing any risk after receiving the relevant information. Psychologists have consistently shown that a system of cognitive mechanisms, known as the psychological immune system,[102] operates to ameliorate the experience of negative affect. Thus any distress that people experience upon learning adverse medical results, which might include the increased risk of a genetic condition, is likely to subside as the person's psychological immune system kicks in,[103] thereby making it

99. Heaton and Chico, 'Attitudes Towards the Sharing'.
100. Heaton and Chico, 'Attitudes Towards the Sharing'. This study found that 25–40% of participants did not want to know about non-preventable genetic conditions.
101. *ABC*, para 13.
102. D.T. Gilbert, E.C. Pinel, T.D. Wilson, et al. 'Immune Neglect: A Source of Durability Bias in Affective Forecasting' *Journal of Personality and Social Psycho*logy 75 (1998), pp. 617–638.
103. For a more detailed account of the psychological immune system, see J.A. Blumenthal, 'Law and the Emotions: The Problems of Affective Forecasting', *Indiana Law Journal* 80 (2004), pp. 155–238; D.T. Gilbert, E. Driver-Linn and T.D. Wilson, 'The Trouble with Vronsky: Impact Bias in the Forecasting of Future Affective States', in L.F. Barrett and

unlikely that a recognized psychiatric condition will result from knowing actionable genetic information.[104]

A duty would be too burdensome

The third reason Nicol J. felt that it would not be just, fair and reasonable to impose a duty to disclose genetic risk information on doctors was because it would be too burdensome and would be a distraction from treating patients. However, the preceding discussions of confidentiality and the interest in not knowing demonstrate that limiting the duty to disclose to actionable risks puts significant boundaries around the duty which arguably make it workable. In addition to these limiting mechanisms, most genetic conditions are not currently preventable or treatable. This means that the duty to disclose information would only crystallize in relation to a small number of genetic conditions. Indeed when a working group of the American College of Medical Genetics and Genomics (ACMG) sought to construct a list of genetic 'disorders where preventative measures and/or treatments were available',[105] the list contained only 24 conditions relating to 57 genetic mutations.[106] Furthermore many of these disorders are very rare. All of this combines to mean that it would be a very rare occasion where a doctor is in receipt of genetic risk information, concerning a preventable condition, which would be useful to a patient's relative, who has no knowledge of the risk through family history, in a situation where the patient objects to their relative having this information. From this perspective a duty to disclose actionable genetic information to patients' relatives is unlikely to represent the burden Nicol J. suggests and, moreover, has the potential to save lives and contribute to the knowledge about the genetic condition which affects the patient. These counter arguments to Nicol J.'s policy concerns demonstrate how non-disclosure of genetic information could realistically be perceived to be a wrong for which a duty of care is owed where that non-disclosure leads to actionable harm. In these circumstances, declining to impose a duty of care on the basis that it would offend the notion of incrementalism may well lead to a situation where the legal approach to the disclosure of genetic risks does not reflect the perspectives of the relevant professionals and the public. It

P. Salovey (eds) *The Wisdom in Feeling: Psychological Processes in Emotional Intelligence* (New York: Guilford Press, 2002), pp. 114–143.

104. See my extended case comment on *ABC* which focuses on the potential psychiatric harm claim in the case. V. Chico, 'Doctors Under no Duty'.

105. R.C. Green, J.S. Berg, W.W. Grody, et al., 'ACMG Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing', *Genetics in Medicine* 15 (2013), pp. 565–574. This list was for the purpose of determining the incidental findings, which might arise in whole exome or whole genome sequencing, that patients could not originally opt out of receiving.

106. Similar exercises in the United Kingdom have led to much smaller lists of preventable conditions. Genomics England allows patients to opt-in to feedback of a small number of looked-for additional clinically important findings. Available at: http://www.genomicsengland.co.uk/wpcontent/uploads/2015/03/GenomicEnglandProtocol_030315_v8.pdf (accessed 16 February 2016).

might be argued that public reactions to legal decisions which fail to reflect public opinion set the platform for the kind of incremental development which has historically been problematic in English law.[107] Thus in the light of the evidence of public and professional views portrayed here, an approach which does adopt an extension of the duty of care might bypass the problematic aspects of incrementalism that we have seen in wrongful birth and psychiatric harm leading to these being areas of the law that are universally subjected to criticism.[108]

Conclusion

Unlike the 'wrongful birth' litigation, Nicol J. did not base his decision on the views of ordinary people in *ABC*. Despite this, health professionals' responsibilities to patients' families to disclose information about elevated genetic risks seems to be an issue which is of interest to the general public and, thus, one upon which they form strong views. The empirical evidence cited here indicates that the decision not to impose a duty on doctors to disclose information about avoidable genetic disease is not likely to be popular with the public because they want to have, and share, this information, and they do not put significant emphasis on confidentiality in these circumstances. If this is an issue upon which the public has a view, and moreover a strong view, a legal decision which goes against evidence of public opinion will require significant justification if it is to receive public support. It is argued that the policy concerns cited by Nicol J. in *ABC* do not provide a sufficiently significant justification for not imposing a duty to disclose in the context of actionable genetic information. As knowledge about the relevance of genetic information increases, we may find that there is little public support for the decision in *ABC*. Indeed there is already a strong academic criticism of the case.[109] If this position is maintained in the Court of Appeal, the reaction of ordinary people might influence a future court to change its position to fulfil its role of reflecting the interests of society. In the wrongful birth litigation, the incremental development of the narrow view of what people would be prepared to view as harmful led to an inconsistent approach based on immaterial differences. In the context of non-disclosure of avoidable genetic risks evidence of the desire to receive and share genetic information suggests that people are readily motivated to perceive harm and a corresponding wrong if information is not disclosed. If a result which reflects public opinion is achieved from the outset in the context of disclosure of genetic information to at risk relatives, this will prevent the need to introduce immaterial distinctions to reflect public opinion, thereby preventing this area from becoming the next bad example of incremental development in the tort of negligence.

---

107. As with the perception of the public view of the initial differing legal response to the claims of the families and the police officers after the Hillsborough disaster.
108. Stapleton, 'Restraint of Tort'.
109. See for example, R. Gilbar and C. Foster, 'Doctors Liability to the Patient in Genetic Medicine', *ABC v. St George's Healthcare NHS trust* [2015] EWHC 1394 (QB) *Medical Law Review* 24 (2015), pp 112–123.

Acknowledgements

I am grateful to Colin Mitchell and the two anonymous reviewers for their thoughtful comments on this article which enabled me to significantly improve it.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.