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# Known unknowns and unknown unknowns: the potential and the limits of autonomy in disclosure of genetic risk

*Victoria Chico*

## Introduction

This article considers the potential grievance that might arise where there is an unwanted disclosure of genetic information. Specifically, it is argued that disclosure of genetic information can interfere with personal autonomy. In the context of this argument a distinction is made between the disclosure of unknown unknowns and known unknowns.<sup>1</sup> An unknown unknown occurs where I have not considered the potential existence of the (genetic) information prior to disclosure and therefore had not declined to receive it. A known unknown arises where I am aware of the possible existence of (genetic) information and its characteristics but I am not aware of the exact content of that information. For example I might have directed my mind to the possibility that information about my risk of a particular genetic condition, say Alzheimer's disease, has been or has possibly been generated but I may not want to know in figurative terms what my risk is. It is argued here that the knowledge that I have in the known unknown scenario makes it possible for me to exercise my autonomy in a way which I cannot with regard to unknown unknowns. Following this, assume I exercise my autonomy and decide not to know the particular characteristics of the information; however, someone informs me in any event and I am significantly aggrieved. Would I have any legal redress? Currently, within English law, probably not. This article considers the potential articulation of such a grievance within the tort of negligence. In particular it considers how a hypothetical English tort of negligence which is explicitly imbued with recognition of the interest in autonomy might respond to this claim.

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1 I am aware that this Rumsfeldian terminology has been criticised most famously by the Plain English Campaign. Rumsfeld was awarded the 2003 Foot in Mouth Award for his known unknown, unknown unknowns comment in a press briefing <http://www.plainenglish.co.uk/awards/foot-in-mouth-award.html> retrieved 19/07/2012. However, others have praised his language as 'completely straightforward' and 'impeccable, syntactically, semantically, logically, and rhetorically. There is nothing baffling about its language at all'. Geoffrey K Pullum Professor of General Linguistics, University of Edinburgh. (2003-12-02). "[Language Log: No foot in mouth](#)" retrieved 19/07/2012. See also Mark Steyn who called Rumsfeld's quote 'a brilliant distillation of quite a complex matter'. M. Steyn (December 9, 2003). 'Rummy speaks the truth, not gobbledygook' Daily Telegraph. <http://www.telegraph.co.uk/comment/personal-view/3599959/Rummy-speaks-the-truth-not-gobbledygook.html>. Retrieved 19/07/2012.

## Autonomy and the approach to damages and duties in negligence

Autonomy is a multi-faceted concept. However, it seems to be constant across conceptions that self-direction is the central element.<sup>2</sup> In the context of medical decisions autonomy finds its expression through consent. Although it might be argued that English law does not have a clear doctrine of informed consent,<sup>3</sup> an obvious relationship exists between information and consent. Indeed, in the context of medical decision making it has long been recognised that a decision must be freely made with sufficient *information* and understanding if it is to be autonomous.<sup>4</sup>

The idea of self-direction which lies at the heart of autonomy relates to having control to shape your own life in your own way. On the face of it, to meaningfully control your own life you need to be aware of information about yourself which would influence how you exercise control. Information about personal health risks might determine how control is exercised. Where the individual has the personal information required for self-determination, we protect autonomy by allowing the person to be self-determining. However, where personal information required for self-determination is lacking, the interest in autonomy is protected by providing that information. In the context of an unknown unknown the individual cannot be self-determining with regard to the decision about the disclosure of the information itself, but the disclosure provides the knowledge which promotes self-determination in future decisions. However, problems arise with regard to the relationship between information about the self and self-determination where the individual knows there is information to know but chooses not to know that information. Can the potential discloser base the interest in not knowing this information on the argument that knowing it would infringe his or her autonomy? In part this might depend on whether the information is considered relevant. Indeed in the context of consent to medical treatment every possible risk need not be disclosed in order for the person to make an autonomous choice.<sup>5</sup> Relevance is not a binary concept. In our daily lives we regularly distinguish between degrees of relevancy. In the context of information disclosure, information is relevant where it has a causal relationship with a decision or behaviour. However, the way that we are influenced by information is subjective. Thus information which is causally relevant to one person may not be to another. English law finds it difficult to account for the subjective nature of relevance in the context of consent to medical treatment. What physicians think will be causally relevant in patients'

2 See, for example, G. Dworkin, *The Theory and Practice of Autonomy* (1988) Cambridge: Cambridge University Press); R. Young, 'The Value of Autonomy' 32 (1982) *The Philosophical Quarterly* 35; L. Waddell-Ekstrom, 'A Coherence Theory of Autonomy' *Philosophy and Phenomenological Research* 53 (1993) 599; J. Christman, 'Constructing the Inner Citadel: Recent Work on the Concept of Autonomy' 99 (1988) *Ethics* 109 and R. Young, 'Autonomy and Socialization' 356 (1980) *Mind* 567.

3 See the development of the law on non-disclosure of risks in medical treatment from *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871; *Pearce v United Bristol Healthcare NHS Trust* [1998] 48 BMLR 118; *Chester v Afshar* [2005] 1 AC 134 and *Birch v UCL NHS Foundation Trust* [2008] EWHC 2237.

4 S. Pattinson, *Medical Law and Ethics* (2011 3rd edition London: Sweet & Maxwell) 115.

5 See, for example, *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871; *Pearce v United Bristol Healthcare NHS Trust* [1998] 48 BMLR 118.

decisions often does not accord with patients' opinions.<sup>6</sup> Furthermore, a patient focused test<sup>7</sup> is unlikely to be nuanced enough to take account of the ways that different patients might be influenced by the particular information. Thus adopting some objective position which reflects people's views on what information is relevant is inherently difficult. Given this where the opportunity for individuals to determine themselves what they deem to be relevant is lacking, any information which says something reliable about those individuals has the potential to be relevant. Autonomy is then about all personal information rather than some personal information. People may get some information that has no causal effect with regard to changing actions or decisions, but this information is still relevant because being causally implicated in choosing not to change your behaviour or not to make different decisions based on particular information requires having that information. Where information is not disclosed, the responsibility for not realising options based on the information rests with nature or whoever withheld the information rather than the person whom the information is about.<sup>8</sup>

## Recognition of autonomy in the tort of negligence

Damage is the gist of the action in negligence.<sup>9</sup> Historically, physical, and more recently, tangible damage are exclusively the types of damage which tort law recognises.<sup>10</sup> The further the perceived adverse outcome is from this corporeal paradigm the more difficult it becomes to refer to it as damage in negligence.<sup>11</sup> Disrespecting the interest in autonomy does not fit within the current parameters of damage in negligence. It is simply not seen as equivalent to the tangible damage that tort law recognises. Despite this the interest in autonomy is well recognised within the tort of trespass to the person,<sup>12</sup> and in the jurisprudence relating to Article 8 of the European Convention of Human Rights.<sup>13</sup> However, the increasing importance of autonomy appears to have had an effect in two fairly recent House of Lords negligence cases. In *Rees v Darlington Memorial Hospital NHS Trust*,<sup>14</sup> and *Chester v Afshar*<sup>15</sup> their Lordships demonstrated a tentative willingness to provide redress for negligently inflicted damage to autonomy interests. In *Rees* the House awarded compensation to Ms Rees based on the birth of her healthy son, despite

6 See, for example, *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871; *Pearce v United Bristol Healthcare NHS Trust* [1998] 48 BMLR 118; *Chester v Afshar* [2005] 1 AC 134 and *Birch v UCL NHS Foundation Trust* [2008] EWHC 2237.

7 Like that discussed by Lord Bridge in *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871, 900 and Lord Woolf MR in *Pearce v United Bristol Healthcare NHS Trust* [1998] 48 BMLR 118, 123.

8 For support see T. Hurka, 'Why Value Autonomy?' 13 (1987) *Social Theory and Practice* 361, 366.

9 J. Stapleton, 'The Gist of Negligence. Part I: Minimum Actionable Damage' 104 (1988) *Law Quarterly Review* 213.

10 Thanks are due to one of the anonymous reviewers for providing a form of words which brought clarity to this point.

11 N. Prialux, 'Joy to the World! A (Healthy) Child is Born! Reconceptualizing 'Harm' in Wrongful Conception 13 (2004) *Social and Legal Studies* 5, rendering an interpretation of J. Feinburg, *Harm to Others* Oxford: Oxford University Press (1984) 33.

12 See for example, *Re B Adult: Refusal of Medical treatment* [2002] 2 FCR 1; 1090; *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936; *R v Collins Ex p S (No. 2)* [1999] Fam 26.

13 See for example, *NHS Trust A v M, NHS Trust B v H* [2001] Fam 348; *R (On the Application of Purdy) v DPP* [2009] UKHL 45, Lord Hope, 34-43.

14 [2004] 1 AC 309.

15 [2005] 1 AC 134.

the fact that in *McFarlane v Tayside Health Board*<sup>16</sup> it had refused to recognise the birth of a healthy child as damage. Their Lordships sidestepped *McFarlane* by awarding Ms Rees a ‘conventional sum’ which, rather than reflecting the costs of raising her child, was intended to compensate for the interference with her autonomy.<sup>17</sup>

Shortly after *Rees* the House of Lords again indicated that interference with the interest in autonomy might be recognised as a form of ‘damage’ within the tort of negligence. In *Chester v Afshar* a surgeon, Mr Afshar, negligently failed to inform Miss Chester of the risk of paralysis inherent in spinal surgery. When Miss Chester suffered paralysis she claimed that she would not have had the operation on that occasion but that she would probably have had it at some point in the future. Miss Chester could not, therefore, overcome the traditional ‘but-for’ test for factual causation. Despite this, the majority held that she should be compensated, on the basis that the law should protect the patient’s right to make informed choices about medical treatment.<sup>18</sup> Lord Steyn said:

‘A rule requiring a doctor to abstain from performing an operation without the informed consent of a patient .....ensures that due respect is given to the autonomy and dignity of each patient.’<sup>19</sup>

These cases demonstrate some willingness to recognise that autonomy is an interest which deserves some legal protection in the tort of negligence.<sup>20</sup>

The interest in autonomy which is protected by not knowing genetic information has been recognised by two international instruments which are credited with playing a crucial role in establishing rights in the genetic context.<sup>21</sup> Article 10(2) of the Council of Europe Convention on Human Rights and Biomedicine states:

‘Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.’

Similarly, Article 5c of the UNESCO Universal Declaration on the Human Genome and Human Rights states:

‘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.’

This international recognition of the interest in not knowing and the tentative willingness of our senior judges to recognise that breach of autonomy might deserve some protection

16 [2000] 2 AC 59.

17 *Rees v Darlington Memorial Hospital NHS Trust* [2004] 1 AC 309, Lord Millett 349.

18 *Chester v Afshar* [2005] 1 AC 134, Lord Hope 162; Lord Walker 164; Lord Steyn 144.

19 *Ibid* Lord Steyn 144.

20 Compensatory damages are awarded for loss. However, in these two cases the nature of the loss was not clear. The loss which was compensated was not a direct result of the breach of the interest that the House explicitly recognised as requiring vindication. It might be argued that in these cases the House was awarding vindicatory damages. This raises important questions about tort law as a means of vindicating rights rather than compensating loss. In a recent case the Supreme Court declined to award vindicatory damages for false imprisonment. Furthermore, the majority doubted whether such a head of damages actually existed. Thanks go to one of the anonymous reviewers for raising this issue. See *Walumba Lumba v Secretary of State for the Home Department* [2011] UKSC 12.

21 G. Laurie, ‘Genetics and Patients’ Rights: Where are the Limits?’ 5 (2000) *Medical Law International* 25, 26.

in negligence indicates that there is potential for English law to recognise that a person can be harmed by receipt of information that he or she did not want.

In negligence the definition and categorisation of damage tends to be dealt with under the concept of duty of care.<sup>22</sup> If interference with autonomy through disclosure of genetic information is recognised as harm in negligence, a corresponding duty might be imposed on those in a position to disclose genetic information not to cause that harm. Health professionals could be subject to such a duty. In order to fulfil a duty, the person who owes the duty must know what fulfilment entails. Foreseeability is the key here. Whilst people might be able to foresee harm when their actions may cause physical harm, they may not be able to foresee whether a particular action will breach autonomy because people are likely to react, and interpret its impact upon their autonomy, differently. This is particularly true with regard to the question of knowing or not knowing personal genetic information. Here it is not the case that one or the other of the particular situations (knowing or not knowing) is seen as detrimental *per se*; it depends on the particular individual and his or her desires regarding receipt of genetic information. Thus the question of whether damage has occurred depends not only on what takes place but also on the individual's attitude to it.<sup>23</sup> This means that what amounts to damage in some cases might not amount to damage in others. Indeed some situations which many people would consider to be beneficial might be considered to be deleterious to a particular individual.<sup>24</sup> The question is whether the tort of negligence is equipped to recognise a particular result as damaging when that result would not be uniformly perceived as harmful? In terms of the imposition of a duty of care, a crucial issue here is likely to be whether the potential defendant could have foreseen that this particular individual would perceive the particular outcome as deleterious. There may be a pre-tort relationship between the parties in which the explicit or implicit actions of the potential claimant indicate that she will perceive a particular result as damaging even though the majority of people would not view the result in this way. Indeed, the potential claimant may have sought out the potential defendant to help him or her to avoid that result.<sup>25</sup> In these circumstances even though the foreseeability of harm would depend on individual desires, it is clear beforehand what the person's desires are making it possible, practically, to impose achievable duties.

If autonomy is upheld by respecting a person's decisions and actions irrespective of their content, this element of foreseeability might be achievable in relation to known unknowns.<sup>26</sup> However, it is not achievable in relation to unknown unknowns.<sup>27</sup> In relation to the latter a duty to protect autonomy could only rest on a conception of autonomy which has objective substance and does not simply rest on fulfilling individual desires. In this case it would be clear to the person charged with the duty how they might discharge it. Indeed negligence

22 For explicit judicial pronouncements of this fact see, for example, *Sutherland Shire Council v Heyman* (1985) 59 ALJR 564 Brennan J 564, 590; *Caparo Industries plc v Dickman* [1990] 2 AC 605, Lord Bridge 618, 627 and Lord Oliver 651.

23 D. Nolan, 'New Forms of Damage in Negligence' 70 (2007) *Modern Law Review* 59, 71–77.

24 This is demonstrated in the claims arising from unwanted pregnancies.

25 For example where an individual has approached a surgeon for a sterilisation/contraception it is clear to the surgeon that she will not view a subsequent pregnancy as beneficial. Another example might be where parents approach a fertility clinic to assist them to bear a saviour sibling for an existing sick child. When providing this service the clinic test the tissue type of the embryos the parents produce through IVF and select one that matches the tissue type of the existing child. The parents might not view a pregnancy (or the birth of the child) as beneficial if they subsequently discover that the medical team carelessly transferred an embryo with the wrong tissue type.

26 Where the individual has expressed her desire not to be informed.

27 Where the individual was not previously aware there was something to know.

law is premised on objectivity. Thus the law might find it easier to recognise new forms of damage if they are objectively determined. However, this raises many questions with regard to recognising breach of autonomy as damage because autonomy is characteristically a subjective value. However, let us consider whether we can construct conceptions of autonomy which have an element of objectivity such that the law might be able to gain the analytical purchase required to recognise breach of autonomy as damage. Two potential options are analysed in the section below: the concept of an objective idea of what people want to know and the idea that knowing is fundamental to autonomy such that the concept of autonomy always requires knowing and cannot, therefore, justify not knowing.

## Autonomy and the interest in not knowing an unknown unknown

Where it is not known whether someone wants to know information about his or her genetic risks, the argument that non disclosure is justified by the concept of autonomy may be based on the idea that there are clear patterns in what people generally want to know and do not want to know. If this is the case, we can know what an individual would want simply from the nature of the information. The problem with this is that it seems to remove the element of self-determination which was argued above to be the central unifying principle of autonomy. Nevertheless let us consider this prospect in more detail. Assume we are dealing with a clear cut scenario where one option is particularly terrible such that it is reasonable to assume that almost everyone would choose the same thing. Here it might be possible to justify adopting a course of action in relation to a particular individual on the basis of autonomy because acting in that way towards them would mimic their self-determinative action. In effect we would be saying we know they would choose to act in this way so we will act in this way to protect their autonomy.<sup>28</sup> Of course this raises the question of what such a clear cut situation might be. But duties in negligence already rest on the basis that no one would want to be physically, mentally or financially harmed by another's negligence. Indeed Mullender argues that the protective purpose of the tort of negligence maintains a commitment to the ideal of personal autonomy.<sup>29</sup> The question is whether such certainties can also be stated in the context of knowing and not knowing personal genetic information.<sup>30</sup>

In terms of certainties, it might be argued that practically everyone would want to know about a particular genetic risk if they could access simple, effective prophylactic treatment.<sup>31</sup> But short of this it is difficult to be certain about what people generally would

28 Furthermore, it becomes difficult to distinguish between autonomy and welfare here.

29 R. Mullender, *English Negligence Law as a Human Practice* 21 (2009) *Law and Literature* 321, 324–325.

30 This, of course, goes to the heart of the issue of foreseeability of harm in the context of the disclosure of genetic information discussed above on pages 5–6.

31 The uptake rate for predictive genetic testing for familial adenomatous polyposis (FAP) is around 80%. D.G.R. Evans, E.R. Maher, R. MacLean, D.R. Davies and D. Craufurd, 'Uptake of Genetic Testing for Cancer Predisposition – Ethical Issues' 34 (1997) *Journal of Medical Genetics* 746. This condition can be prevented prophylactically by surgically removing the colon. This is a significant undertaking but despite this there is still a high uptake rate. If treatment were much simpler, the uptake rate might be higher. Moreover, the rate of uptake should not be taken as a direct indicator of people's desire to know about their risk per se. People might have a greater desire to know information that already exists about them than they might to confirm a risk that they are already aware of. That is, people with dominant autosomal genetic conditions such as Huntington's Chorea and FAP will already be aware of their risk because of their families history. Taking a test themselves will add certainty to the already known risk.

and would not want to know about their genetic risks. Whilst some people might not want information concerning unavoidable risks, others may be eager to know all they can so that they can prepare. The uptake of predictive testing for Huntington's Disease, for which there is currently no treatment, is relatively low,<sup>32</sup> (around 5–25 per cent in the UK and elsewhere),<sup>33</sup> but it is not insignificant enough to justify a wholesale conclusion that people do not want to know. Furthermore, evidence demonstrates an uptake rate of around 50 per cent in testing for many genetic conditions which can be managed but not cured.<sup>34</sup> Of course people who access predictive genetic testing will usually already be aware of their elevated risk because of their family history. The test confirms the presence or absence of the gene. Given this, the evidence of uptake rates here is not directly indicative of what people would want to be told 'out of the blue' in terms of risks of which they were not previously aware. However, there is no specific evidence indicating what people want to be informed of 'out of the blue' so the uptake rates for predictive testing are the only relevant indicators of desires in this context. The equivocal nature of the evidence of uptake rates makes it impossible to make generalisations which purport to reflect self-determination about when people would and would not want to know about their genetic risks.

This moves us on to our second line of thought concerning the preservation of autonomy in relation to unknown unknowns. If self-determination is the crux of autonomy, where self-determination is impossible, an objective position may be established where autonomy is protected by maximising future opportunities for self-determination.

Some philosophers argue that a crucial aspect of autonomy is the possession of information which enables meaningful self-determination.<sup>35</sup> According to Aristotle 'all men desire to know'.<sup>36</sup> Similarly Harris and Keywood argue that there is a normal and reasonable presumption of a relationship between information and autonomy.<sup>37</sup> Others agree that relevant information is crucial in forming autonomous desires and making

32 When compared to conditions for which there is some treatment or avoidance strategy.

33 M.R. Hayden, 'Predictive Testing for Huntington's Disease: The Calm After the Storm' 356 (2000) *The Lancet* 1944. As Hayden acknowledges, this was significantly less than the 70–80 per cent uptake that had been predicted before testing was available.

34 This rate of uptake provides little assistance in determining what the majority of ordinary people might want to know, thereby providing little assistance in pouring content into the concept of objective autonomy. See, for example, I. Christiaans, E. Birnie, G.J. Bonsel, A.A.M. Wilde and I.M. van Langen, 'Uptake of Genetic Counselling and Predictive DNA Testing in Hypertrophic Cardiomyopathy' 16 (2008) *European Journal of Human Genetics* 1201, this study demonstrated that the uptake for predictive genetic testing for hypertrophic cardiomyopathy after detection of the causal mutation in the proband was 39 per cent. Prevention of sudden cardiac death in patients with a high risk by means of an implantable cardioverter defibrillator is effective in this condition; M.E. Ropka, J. Wenzel, E.K. Phillips, M. Siadat and J.T. Philbrick, 'Uptake Rates for Breast Cancer Genetic Testing: A Systematic Review' 15 (2006) *Cancer Epidemiology, Biomarkers & Prevention* 840, where a systematic review of 40 studies revealed a real uptake rate of 59 per cent of various forms of predictive testing for breast cancer.

35 J. Harris and K. Keywood, 'Ignorance, Information and Autonomy' 22 (2001) *Theoretical Medicine* 415; R. Rhodes, 'Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge' 23 (1998) *Journal of Medicine and Philosophy* 10; For an account of how autonomy is not necessarily restricted by a lack of information see J. S Taylor, 'Autonomy and Informed Consent a Much Misunderstood Relationship' 38 (2004) *The Journal of Value Inquiry* 383 L.O. Ursin, 'Personal Autonomy and Informed Consent' 12 (2009) *Medicine, Healthcare and Philosophy* 17; G. Dworkin, 'Autonomy and Behaviour Control' 6 (1976) *Hastings Center Report* 23.

36 W.D. Ross, (ed.) *Aristotelis Topica et Sophistici Elenchii* (1958 Oxford: Clarendon Press) 1.

37 J. Harris and K. Keywood, 'Ignorance, Information and Autonomy' 22 (2001) *Theoretical Medicine* 415, 417.



autonomous choices.<sup>38</sup> For Harris and Keywood autonomy finds expression through the law of consent, where the emphasis is firmly on the provision of relevant information.<sup>39</sup> Consent, where one is capable of it, is vitiated when it is ill-informed.<sup>40</sup> Failures to provide adequate information regarding the risks of, or the nature of, medical treatment are actionable in negligence and battery respectively. Traditionally the doctrine of therapeutic privilege allowed doctors to discretionally withhold information from patients where it was thought that the disclosure would harm the patient. However, General Medical Council (GMC) guidance suggests that in modern medicine this privilege is confined to very narrow circumstances, where disclosure would cause 'serious harm' which excludes the patient becoming upset, or refusing treatment.<sup>41</sup> Thus, the contemporary assumption is that the patient wants, and can cope with, the relevant information and that it should be disclosed to allow competent patients to form autonomous desires and choices.<sup>42</sup> In the genetic information scenario where it is not known that there is information to be known, the opportunity for self-determination does not arise. In the circumstances it might be argued that autonomy would be maximised by facilitating future self-determination. Disclosure would provide information about the self which could enable future self-determination. Thus, in relation to unknown unknowns, if health professionals were under a duty to protect the autonomy of those whose genetic information they come into contact with, they would discharge this duty by disclosing the information.<sup>43</sup> An aggrieved individual might subsequently argue that he or she would rather not have

38 See, for example, R. Rhodes, 'Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge' 23 (1998) *Journal of Medicine and Philosophy* 10, 17–18; G. Laurie, 'The Most Personal Information of All: An Appraisal of Genetic Privacy in the Shadow of the Human Genome Project' 10 (1996) *International Journal of Law, Policy and the Family* 74, 87; G. Laurie, 'Protecting and Promoting Privacy in an Uncertain World: Further Defences of Ignorance and the Right not to Know' (2000) 7 *European Journal of Health Law* 185, 189.

39 J. Harris and K. Keywood, 'Ignorance, Information and Autonomy' 22 (2001) *Theoretical Medicine* 415, 417.

40 J. Harris, *The Value of Life* (1985 London: Routledge) Chapter Ten.

41 General Medical Council, *Consent, Patients and Doctors Making Decisions Together* London, 2008, paragraph 16.

42 Although historically there might have been a tendency on behalf of the medical profession to withhold information from patients, on the basis that the patient might be too naïve or sensitive to cope with that information, this position is now generally accepted as being unduly paternalistic.

43 Of course one of the major problems with imposing a duty here is that English negligence law does not usually impose liability for pure omissions. *Smith v Littlewoods Organisation Ltd.* [1987] AC 241 Lord Goff 271. One area of English law which falls within the context of omissions is liability for the acts of third parties. An analogy might be drawn between this area of law and the situation considered here. It is assumed here that the reason the health professional is aware of the particular person's genetic risk is because of a test they have performed on the person's relative. Although this scenario might not be about controlling the third party as such, this body of law might be relevant for its take on special relationships in this tripartite scenario. Exceptions to the rule that there is no liability for the actions of others have been carved out in the context of special relationships where there is proximity imported by control or a special relationship *Home Office v Dorset Yacht Co. Ltd.* [1970] AC 1004. So far the English courts have been unwilling to impose liability where they do not consider there is no duty to control which can be relied on to establish a clear special relationship between the defendant and the third party or the defendant and the claimant. See *Hill v Chief Constable of West Yorkshire* [1989] AC 53 and *Palmer v Tees HA* [2000] PIQR P1. However, I have argued elsewhere that identifiability of risk might be a more suitable than control as a basis for imposing liability on health professionals for omissions with regard to information disclosure. V. Chico *Genomic Negligence: An Interest in Autonomy as the Basis for Novel Negligence Claims Generated by Genetic Technology* (2011) Routledge Cavendish 161–170. In the USA there is a fairly well developed body of law concerning the failure to disclose information about medical, including genetic, risks which does not rely on an element of control to found a special relationship. See in particular *Tarasoff v Regents of the University of California* 551 P.2d 334 (Cal 1976), *Pate v Threlkel* 661 So. 2d 278 (Fla. 1995) and *Safer v Pack A.* 2d 1188 (NJ Super. Ct. App. Div. 1996) and again the argument I have made previously in V. Chico *Genomic Negligence: An Interest in Autonomy as the Basis for Novel Negligence Claims Generated by Genetic Technology* (2011) Routledge Cavendish 161–170.

had that information; however, the disclosure cannot amount to an interference with autonomy, because autonomy is protected through the promotion of self-knowledge and the opportunity for future self-determination. Given that self-determination with regard to the instant decision is impossible, from this perspective, there could then be no duty on healthcare professionals to ensure non-disclosure which could be justified by recourse to the principle of autonomy.

## **Autonomy and the interest in not knowing a known unknown**

Although it has been argued here that the interest in not knowing an *unknown* unknown cannot be justified by recourse to the principle of autonomy, it might be argued that the interest in not knowing a *known* unknown can be justified on this basis.<sup>44</sup> Assume that an individual has stipulated, in a way readily discoverable by health professionals, that he or she does not want to know information about elevated genetic risks. However, ignoring this direction, a health professional informs the individual of his or her elevated risk which the professional is aware of because of a genetic test performed on a relative. Here there is a prior choice not to be informed, which represents the individual's wishes.

### ***Autonomy and substantive rationality***

Where the individual has expressed a wish not to know specific genetic information, he or she is aware that there is information, or potential information to know as well as the nature of that information, in essence then he or she knows what it is that remains unknown. Does the individual possess the knowledge about him or herself sufficient for self-determination in these circumstances? At the very least the individual has directed his or her mind to the issue in deciding not to have the information. Nevertheless, following on from the above argument<sup>45</sup> we could claim that a refusal of information can never be justified on the basis of autonomy because lack of information prevents meaningful self-determination.<sup>46</sup> On this basis, the health professional would not interfere with the individual's autonomy in disclosing the information even if this is contrary to the recipient's expressed wishes because only acceptances of information are autonomous.

Rhodes argues that the interest in not knowing cannot be based on autonomy where the information is relevant to making rational decisions. She links the concept of rationality to the reasonable person and the information which that person would want to know. She says:

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44 See for example G. Laurie, 'The Most Personal Information of All: An Appraisal of Genetic Privacy in the Shadow of the Human Genome Project' 10 (1006) *International Journal of Law, Policy and the Family* 74; G. Laurie, 'Obligations Arising from Genetic Information – Negligence and the Protection of Familial Interests' 11 (1999) *Child and Family Law Quarterly*; G. Laurie, 'Genetics and Patients' Rights: Where are the Limits?' 5 (2000) *Medical Law International* 25; G. Laurie, 'Protecting and Promoting Privacy in an Uncertain World: Further Defences of Ignorance and the Right Not to Know' 7 (2000) *European Journal of Health Law* 185; G. Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (2002 Cambridge: Cambridge University Press).

45 Made in relation to unknown unknowns.

46 A concept put forward here as a unifying central element in conceptions of autonomy.

'I am obligated to make thoughtful and informed decisions without being swayed by irrational emotions including my fear of knowing significant genetic facts about myself. When I recognize that I am ethically required to be autonomous, I must also see that since autonomous action requires being informed of what a reasonable person would want to know under the circumstance, I am ethically required to be informed.'

This suggests that a refusal to receive genetic information which reasonable people would want to know cannot be justified on the basis of autonomy because it is not rational, and rationality is a precondition of autonomy. Let us put aside the objection that rationality and reasonableness are not the same thing. From a legal perspective, if the courts were minded to protect autonomy with regard to the disclosure of genetic information, they might find that the notion of the reasonable person provides a *legally* workable basis upon which to recognise both the interest in knowing and the interest in not knowing. However, the (legal) concept of the reasonable person is a fiction – an artificial judicial creation which, historically, has been relied on to limit the instances in which an action might amount to breach of duty.<sup>47</sup> However, the law is a practical animal. If the law is not practical it has utterly failed.<sup>48</sup> Thus the law needs tools to fulfil its practical function and the standard of the reasonable person is a tool which enables this practical function.

Objectivity is the core feature of the reasonable person. In the context of breach of duty the law assumes the baseline of the careful person. However, the courts have, more recently, relied on the concept of the reasonable person to determine whether a particular outcome ought to be considered damaging and therefore whether people should be under a duty not to cause that particular outcome.<sup>49</sup> Whilst some of our judiciary might question how realistic it is to use objective standards to determine what is harmful,<sup>50</sup> objectivity seems to remain a core feature of their analysis.<sup>51</sup> With respect to breach of duty, we can see that having a subjective test whereby the defendant must prove that he or she acted to the best of his or her own judgment would be impractical. It would 'leave so vague a line as to afford no rule at all, the degree of judgment belonging to each individual being infinitely various'.<sup>52</sup> The practical implication of this would be that people's protection from negligence would depend on the judgment of the particular tortfeasor. If standards operated in such a way, victims of perceived carelessness would be treated inequitably. Furthermore, people might be unwilling to put themselves in the care of others if they could not be confident that baseline standards would be met.

47 *Glasgow Corporation v Muir* [1943] AC 448; *Blyth v Birmingham Waterworks Co.* [1856] 11 Ex Ch 781, Alderson B, 784.

48 C. Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* Oxford: Hart, 2009, 13.

49 In *McFarlane v Tayside Health Board* [2000] 2 AC 59 where Lord Steyn thought it was relevant to ask commuters on the Underground the following question: 'Should the parents of an unwanted but healthy child be able to sue the doctor or hospital for compensation equivalent to the cost of bringing up the child for the years of his or her minority, i.e. until about 18 years?'. More recently Lord Hope showed concern about the ability to make realistic assessments about what reasonable people would consider harmful in a pluralistic society *Chester v Afshar* [2005] 1 AC 134.

50 See, for example, *Chester v Afshar* [2005] 1 AC 134 Lord Hope 161–162.

51 *McFarlane v Tayside Health Board* [2000] 2 AC 59 Lord Steyn 82, *Parkinson v St James and Seacroft NHS* [2002] QB 266 Hospital.

52 *Vaughan v Menlove* (1837) 3 Bng NC 468, 475; 132 ER 490. 493 (Yindal CJ).

The same levels of infinite variability and uncertainty are not present when determining the standard of what amounts to harm. Some circumstances will be viewed almost universally as harmful; such as those concerning corporeal injuries. However, it might be argued that some people will view circumstances which others would deem a benefit as harmful. This position was discussed in relation to pregnancy above. Where a person has done something to indicate that he or she will view circumstances normally considered beneficial as harmful, the circumstances and the way he or she will perceive it are not ambiguous or uncertain.

The value of personal autonomy is, on the face of it, a subjective value which refers to the ability to be your own person to live your life according to your own reasons and motives. The problem with an objective approach based on rules and norms,<sup>53</sup> is that it does not reflect people's real experiences in a way which a subjective inquiry into minds and facts might. Indeed this tension between the subjective nature of the concept of autonomy and the objective basis of the reasonable person, as a means of determining what is harmful in negligence, makes it difficult to envisage how the standard of the reasonable person might be used to determine when a disclosure of genetic information would or would not amount to an interference with autonomy which might be recognised by the law.<sup>54</sup>

Harris and Keywood agree with the argument that self-determination or self-government is central to autonomy. However, they take a line similar to Rhodes and argue that refusals of genetic information cannot be considered to be autonomous because they are not rational.<sup>55</sup> They adopt a conception of autonomy which involves the exercise of control, and argue that ignorance of crucial information is inimical to autonomy because it interferes with the ability to control one's own destiny. They argue that control rather than choice defines self-government and information is crucial to control. They then link the concept of rationality to the principle of self-government arguing that:

'... where the individual is ignorant of information that bears upon rational life choices she is not in a position to be self-governing. If I lack information, for example about how long my life is likely to continue I cannot make rational plans for the rest of my life.'<sup>56</sup>

On this analysis only, decisions which provide for future rationality are autonomous. Thus, in order to make rational life choices in the future, you need to accept relevant information in the present. It seems that the concept of relevance assumes a central role in Harris and Keywood's perception of whether decisions can be rationally made without certain information and correspondingly whether that information can thus be rationally refused.

Information is certainly relevant to a decision where that information causes a particular outcome. For example, giving a person information might lead him or her to seek prophylactic treatment which he or she would otherwise have been unaware of the need for. However, as discussed above, relevance does not only relate to a change in outcome. Hurka argues that autonomy involves choice from a range of options. Thus

53 Which it is argued here is likely to be favoured by English negligence law.

54 I owe thanks to an anonymous reviewer of this article for this argument.

55 J. Harris and K. Keywood, 'Ignorance, Information and Autonomy' 22 (2001) *Theoretical Medicine* 415.

56 *Ibid* 421.

giving a person a choice of ten options respects autonomy in a way which providing him or her with only the highest-ranked choice, the one he or she would have chosen anyway, does not. This, Hurka argues, is because of the individual's causal responsibility for the non-realisation of the other options.<sup>57</sup> Where all ten options are available and the individual chooses option A, he or she is causally responsible for choosing not option B, C, D etc. However, where the individual is only presented with the preferred option A, the causal responsibility for the non-realisation of options B, C, D etc effectively rests with the person who chose not to provide the other options. From this perspective, even where the individual chooses to maintain the status quo upon receiving genetic information – that is, continue with the only option which he or she was aware of prior to the information disclosure – he or she is causally responsible for not choosing the other options which have become open to him or her through the disclosure of the information. In other words, the disclosure of the genetic information makes the person aware of the need to consider options which he or she may not have been aware of in genetic ignorance and, therefore, makes him or her causally responsible for their rejection. On this basis, all genetic information which has significance<sup>58</sup> to a particular person assumes relevance to that person, rather than only that information that would make him or her act differently.

On this account of rational autonomy, it follows that a disclosure of genetic information about an individual to that individual against his or will does not interfere with her autonomy because his or her refusal to receive relevant information was neither rational nor, therefore, autonomous. The concept of autonomy obtains an objective character here. The objective position is that only *failures* to disclose relevant genetic information would interfere with autonomy. The law might find it easier to recognise that breach of autonomy amounts to harm where only failures to disclose information could lead to that harm because the circumstances when the harm can occur will be clearer, consequently making it obvious when a person's actions will amount to a breach of duty. The problem here is separating out the instant and future decisions. From this perspective, the rationality of the present decision to refuse genetic information hinges on the rationality of future decisions as assessed by the ability to control and self-determine those future decisions via the relevant information. However, where the individual knows the characteristics of the information he or she is refusing, it might be argued that he or she is in a position to self-determine in relation to the instant decision because he or she has all the information which is relevant in making this particular decision. That is, the individual knows the characteristics of the information; what he or she does not want to know is the particular level of risk which is contained in that information. If this decision can be considered rational and autonomous because the required element of control exists, why should assessments about opportunities for future control and self-determination affect the ability to be self-determining in the current decision?

Does the problem with the lack of knowledge about the self when refusing genetic information relate to the refusal of the information itself? That is, the individual does not have sufficient knowledge of the content of the information to make a self-determined decision to refuse it. Or rather than the level of knowledge upon which the refusal to receive the genetic information is based, is the problem that the refusal of knowledge

57 T. Hurka, 'Why Value Autonomy?' 13 (1987) *Social Theory and Practice* 361, 362 and 366.

58 In that the information is reliable telling us something about that particular individual's risk.

about the self, although self-determined in this instance because the individual has some knowledge which has enabled him or her to make a decision, is problematic because it prevents opportunities to self-determine in the future?<sup>59</sup> In other words, from a perspective which holds that knowledge about the self is crucial to self-determination, the problem with refusing information about oneself could rest on the fact that the very refusal is not based on sufficient knowledge about the self and therefore it cannot be an exercise of self-determination. Or the problem in terms of the protection of autonomy may not be with the level of knowledge available in the making of the instant decision to refuse genetic information. Instead, it may be that the case that any refusal of such information cannot be justified on the basis of autonomy, even if the refusal itself is sufficiently informed to be an exercise of self-determination.

In the context of the refusal of specific genetic information, it might be argued that where an individual has made an explicit decision to refuse information he or she has clearly considered the possibility of the existence of that information and the personal impact of knowing that information. It is arguable that this level of knowledge about the self is sufficient to self-determinedly refuse the information. However, from the perspective that rationality is a condition of autonomy that necessitates knowing relevant information, an autonomous decision to refuse information about the self is not possible because autonomy supports the giving rather than the withholding of information.<sup>60</sup> Thus, the issue is not that the individual is not self-determining in this instance but that a refusal of genetic information here will diminish the potential for self-determination in the future. So the question is can a self-determining refusal of information ever be justified by autonomy where it will impede future self-determination? Put otherwise, can we autonomously restrict our autonomy? The information as autonomy camp would argue that we cannot. For them autonomy is not content-neutral. Only a choice to accept relevant information would be deemed autonomous. However, we can contend that rationality as a condition of autonomy does not relate to rational ends but to the rationality of the procedure that the decision-maker carries out to achieve those ends. That is, the end in itself does not need to demonstrate a particular value but the procedure needs to be a valid means of reaching ends which are independently desired.

### ***Autonomy and procedural rationality***

According to Dworkin, autonomy is a procedural concept that is characterised by the formula: authenticity + independence = autonomy.<sup>61</sup> In essence, this means that the autonomous person is one who does *his own* thing.<sup>62</sup> This requires an analysis of what it is for a motivation to be *his* and what it is for it to be *his own*.<sup>63</sup> The former relates to authenticity and the latter to independence.<sup>64</sup> In defining authenticity, Dworkin

59 For example treatments or other benefits might emerge which the individual does not have the opportunity to choose because she does not know they are applicable to her.

60 J. Harris and K. Keywood, 'Ignorance, Information and Autonomy' 22 (2001) *Theoretical Medicine* 415, 432.

61 G. Dworkin, 'Autonomy and Behaviour Control' 6 (1976) *Hastings Center Report* 23, 24; G. Dworkin, *The Theory and Practice of Autonomy* (1988 Cambridge: Cambridge University Press) Chapter 1.

62 G. Dworkin, 'Autonomy and Behaviour Control' 6 (1976) *Hastings Center Report* 23, 24 (original emphasis).

63 *Ibid* 24.

64 *Ibid* 24. See, also J. Feinberg, 'Autonomy' in *The Inner Citadel: Essays on Individual Autonomy* J. Christman (ed.) (1989) Oxford: Oxford University Press; R. Young, 'Autonomy and The Inner Self' in *The Inner Citadel: Essays on Individual Autonomy* J. Christman (ed.) (1989) Oxford: Oxford University Press) 79.

distinguishes between first and second order desires and argues that authentic actions require the ability to raise the question of whether one identifies with the motivations for those actions.<sup>65</sup> For example, one may be motivated by jealousy or anger but desire that one's motivations be different.<sup>66</sup> In other words, people are capable of wanting to be different in their preferences and purposes from what they actually are.<sup>67</sup> Thus, authenticity relates to the individual's ability to critically analyse his or her first order motivations and change them if he or she wishes; it is not related to specific ends.<sup>68</sup>

Whilst authenticity is necessary for autonomy, Dworkin argues that it is not sufficient because a person's motivational structure might be his or hers without being his or her own.<sup>69</sup> This may be because the identification with motivations has been influenced in a decisive way by others. Dworkin calls this lack of procedural independence.<sup>70</sup> It does not automatically follow that any interference with an individual's motivational structure prevents procedural independence, such that his or her decisions cannot be considered to be his or her own. Indeed, Dworkin devotes significant attention to distinguishing between those interferences which prevent the individual's decision from being his or her own and those which do not:

'With respect to autonomy conceived of as authenticity under conditions of procedural independence, the paradigms of interference are manipulation and deception, and the analytic task is to distinguish these ways of influencing people's higher order judgements from those (education, requirements of logical thinking, provision of role models) which do not negate procedural independence.'<sup>71</sup>

If authenticity concerns the ability to reflect critically on first order motivations, methods which prevent such reflection will prevent procedural independence. Dworkin argues that it is a feature of persons that they are able to reflect on their decisions, motives, desires, habits and so forth.<sup>72</sup> Thus, influencing people's higher order judgments through education and the provision of role models does not negate procedural independence because they do not affect the ability to critically reflect on motivations. Although manipulative methods such as threats and physical force might not interfere with the knowledge that a particular determinant is influencing behaviour, they may affect the ability to critically reflect on that influence, thereby frustrating procedural independence. Furthermore, subconscious methods of influencing motivation such as subliminal motivation, or the destruction of parts of the brain necessary for performing the critical reflection which authenticity requires, also interfere with procedural independence because the individual does not

65 G. Dworkin, *The Theory and Practice of Autonomy* (1988 Cambridge: Cambridge University Press) 15; Others also support this approach, see, for example, F. Frankfurt, *The Importance of What We Care About: Philosophical Essays*. (1988 Cambridge: Cambridge University Press); J. Feinberg, Autonomy in *The Inner Citadel: Individual Essays on Personal Autonomy* J. Christman (ed.) (1989 Oxford: Oxford University Press) 36–38 on moral authenticity.

66 G. Dworkin, *The Theory and Practice of Autonomy* (1988 Cambridge: Cambridge University Press) 15.

67 H. Frankfurt, 'Freedom of the Will and the Concept of a Person' in *The Inner Citadel: Individual Essays on Personal Autonomy* J. Christman (ed.) (1989 Oxford: Oxford University Press) 64.

68 Such as the acceptance of relevant information considered here.

69 G. Dworkin, 'Autonomy and Behaviour Control' 6 (1976) *Hastings Center Report* 23, 25.

70 *Ibid* 25.

71 *Ibid* 26.

72 *Ibid* 23, 24; See also G. Dworkin, *The Theory and Practice of Autonomy* (1988 Cambridge: Cambridge University Press) 15.

know the real reasons for his or her actions, and therefore, cannot reflect on those reasons and make a favourable or adverse judgment concerning them.<sup>73</sup>

In line with this Dworkin acknowledges that procedural independence may be interfered with where the individual is unaware of relevant facts.<sup>74</sup> However, he goes on to argue that a person who authentically wishes that his or her procedural independence be restricted in certain ways, can act in a procedurally independent manner in renouncing procedural independence such that he or she has acted authentically, and autonomously restricted his or her autonomy.<sup>75</sup>

He says:

‘...a person might decide to renounce his independence of action or thought because he wants (genuinely) to be that sort of person. A person might do whatever his mother, or his government, tells him to do, and do so in a procedurally independent manner.’<sup>76</sup>

He continues, the person who:

‘...wishes to be restricted in various ways, whether by the discipline of the monastery, regimentation of the army, or even by coercion, is not, on that account alone, less autonomous.’<sup>77</sup>

It follows that, where a person authentically and procedurally independently chooses to renounce future independence, that choice cannot be criticised on the basis that it is not procedurally independent. The person is able to reflect; he or she has done, and has made an authentic and independent decision about how he or she wants life to be.

Dworkin maintains that all choices to some extent foreclose other choices, reversibly or irreversibly and such foreclosures need not be viewed as forfeitures of autonomy.<sup>78</sup> If autonomy requires substantive independence, it becomes inconsistent with loyalty, objectivity, commitment, benevolence and love.<sup>79</sup> Consequently, Dworkin argues that a conception of substantive autonomy should not have claim to our respect as an ideal.<sup>80</sup> He maintains that what is important about autonomy ‘...is that the commitments and

73 Ibid 26.

74 Ibid 27.

75 However, others maintain that it is crucial to a procedural account of autonomy that the individual retains control over her decisions and actions. They argue that acts and decisions which appear to be independent but forgo future independence cannot be justified by recourse to the principle of autonomy. On this basis, one cannot defer independent judgment whether to government, moral authority, God or another mere mortal on the basis of autonomy. See, for example, R. Wolff, *In Defense of Anarchism* (1970 New York: Harper & Row) 41; J. Rachels, ‘God and Human Attitudes’ 7 (1971) *Religious Studies* 334; M. Osiel, *Obedying Orders, Atrocity, Military Discipline and the Law of War* (1999 New Jersey: Transaction); R. Rhodes, ‘Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge’ 23 (1998) *Journal of Medicine and Philosophy* 10. It might be argued that this position does not describe procedural autonomy at all but a substantive concept of autonomy where a decision whose content is to renounce future independence is not autonomous because of an error in the substance of the decision rather than in the procedure.

76 G. Dworkin, ‘Autonomy and Behaviour Control’ 6 (1976) *Hastings Center Report* 23, 25; G. Dworkin, *The Theory and Practice of Autonomy* (1988 Cambridge: Cambridge University Press) Chapter 2.

77 G. Dworkin, *The Theory and Practice of Autonomy* (1988 Cambridge: Cambridge University Press) 18.

78 Ibid 26.

79 Ibid 21.

80 Ibid 21 and 25.



promises a person makes be ones he views as his, as part of the person he wants to be, so that he defines himself via those commitments'.<sup>81</sup>

Although Harris and Keywood reject the argument that an appeal can be made to the principle of autonomy to argue that a knowledgeable refusal of relevant genetic information ought to be respected, they concede that there can be legitimate cases of autonomously chosen restrictions on autonomy.<sup>82</sup> However, they distinguish between autonomously chosen restrictions on autonomy which are consistent with autonomy, understood as an ethical principle and such choices which are inconsistent with autonomy.<sup>83</sup> They contrast the monk who enters the monastic order but remains free to leave as an autonomously chosen restriction on autonomy, and the person who sells him or herself into slavery as a choice which is inconsistent with the idea of autonomy, and cannot be protected by appeals to autonomy as a moral principle.<sup>84</sup> The monk remains fully autonomous because although agreeing to be bound, he is still free to choose.<sup>85</sup> Dworkin would not make such a distinction because he believes that what is valuable about autonomy is that the commitments people makes are ones that they view as their own, as part of the person they want to be, so that they define themselves via those commitments. Whether they are long or short term, *prima facie* or absolute, permanent or temporary, is not what contributes to their value.<sup>86</sup>

It is not clear why Harris and Keywood class the choice not to accept genetic information about oneself as akin to the example of the slave rather than the monk.<sup>87</sup> People who choose not to receive information are not bound by the original decision so that they cannot subsequently ask for the information when and if they want it, or when they approach a decision where they feel they want the particular content of the information. Moreover, they can still choose to have genetic tests *themselves* to discover more accurate information about their own genetic constitution than that which they might discover as a result of information which might be generated based on the test taken by a relative.

Dworkin specifically argues that knowledgeable and expressed desires not to know medical information about oneself can be justified by an appeal to autonomy:

'If a patient has knowingly and freely requested of the doctor that he not be informed or consulted about his course of treatment then to seek to obtain informed consent would itself be a denial of autonomy.'<sup>88</sup>

Dworkin's view then is that more knowledge is not always better than less, because there are times when we really do not want to know.<sup>89</sup> Other commentators agree that

81 Ibid 26.

82 J. Harris and K. Keywood, 'Ignorance, Information and Autonomy' 22 (2001) *Theoretical Medicine* 415, 419.

83 Ibid 419.

84 Ibid 420.

85 Ibid 419.

86 G. Dworkin, *The Theory and Practice of Autonomy* (1988) Cambridge: Cambridge University Press, 26. Contrast this view with that of Harris and Keywood regarding when it is possible to autonomously foreclose independence in a way which is consistent with autonomy above.

87 As they argue that it does. J. Harris and K. Keywood, 'Ignorance, Information and Autonomy' 22 (2001) *Theoretical Medicine* 415, 419–421.

88 G. Dworkin, *The Theory and Practice of Autonomy* (1988) Cambridge: Cambridge University Press) 118.

89 G. Dworkin, 'Autonomy and Behaviour Control' 6 (1976) *Hastings Centre Report* 23, 27.

the receipt of information is not always required for a person to act autonomously.<sup>90</sup> From this perspective, simply knowing of the potential existence of the particular genetic information would be sufficient to make an authentic and procedurally independent decision with regard to its acceptance and is sufficient to enable autonomous self-direction. Subsequently, the content of the decision is irrelevant, so a decision to refuse the information can be as autonomous as a decision to accept it.

Although the provision of information is important in English medical law as a means of ensuring patient autonomy,<sup>91</sup> the law does not require that all potentially relevant information is disclosed in order to protect autonomy by way of consent. The tort of battery explicitly protects the patient's autonomy. However, the information disclosure threshold in battery is low because the purpose of the action is to protect people against unwanted touching. Thus, once the patient is informed in broad terms of the nature of the procedure, his or her consent is taken to be effective.<sup>92</sup> On the other hand, with respect to non-disclosure of medical information, negligence protects people where failure to disclose information leads to them run risks which they would not otherwise have run.<sup>93</sup> An action may lie in negligence where the claimant is broadly aware of the nature of the treatment (such that an action in battery cannot succeed) and is aggrieved because of the failure to disclose or draw sufficient attention to a particular risk inherent in the treatment which has then eventuated. However, this does not mean that clinicians must disclose every potential risk before a consent will be deemed to be autonomous. Only those risks which reasonable physicians would disclose or reasonable patients would want to know need<sup>94</sup> to be disclosed before a consent is deemed to be real and consequently autonomous. Thus, in the context of medical decision making the law finds that patient autonomy is protected even though the doctor has not disclosed all potentially relevant information to the patient.

Furthermore, English medical law does allow patients to make choices which foreclose future choices if the original choice is authentic and procedurally independent. In *B v NHS Hospital Trust*<sup>95</sup> the High Court held that a competent individual can refuse medical treatment which will lead to her death, thereby foreclosing any future choices. Thus, the competent adult is not subject to the principle of securing an open future<sup>96</sup> which is relied on to justify overriding a child's current autonomous decision where

90 R. Andorno, 'The Right Not to Know: An Autonomy Based Approach' 30 (2004) *Journal of Medical Ethics* 435; J. Raikka, 'Freedom and a Right (Not) to Know' 12 (1998) *Bioethics* 49, 60; J. Husted, 'Autonomy and a Right Not to Know' in R. Chadwick, M. Levitt and D. Schickle (eds) *The Right to Know and the Right Not to Know*, (1997 Aldershot: Avebury) 55, 67; G. Dworkin, 'Autonomy and Behaviour Control' 6 (1976) *Hastings Center Report* 23; T. Takala, 'The Right to Genetic Ignorance Confirmed' 13 (1999) *Bioethics* 288; L.O. Ursin, 'Personal Autonomy and Informed Consent' 12 (2009) *Medicine Healthcare and Philosophy* 17.

91 See in particular *Chester v Afshar* [2005] 1 AC 134 Lord Hope 161–162.

92 *Chatterton v Gerson* [1981] 1 QB 432, Bristow J 443.

93 Or, following *Chester v Afshar* [2005] 1 AC 134 Would not have run at that time.

94 Depending on the perspective taken from the line of cases dealing with non-disclosure of risk. The pro-defendant position taken in *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871 was questioned in *Pearce v United Bristol Healthcare NHS Trust* [1998] 48 BMLR 118 there has been some development in this area in *Chester v Afshar* [2005] 1 AC 134 and *Birch v UCL NHS Foundation Trust* [2008] EWHC 2237 these cases did not deal directly with the standard with regard to the disclosure of the risks inherent in a particular treatment and have not apparently displaced the position taken in *Sidaway* whereby the doctor will not be negligent in failing to disclose a risk if other reasonable doctors would not have disclosed that risk.

95 *Re B (Adult: Refusal of medical Treatment)* [2002] 2 FCR 1.

96 J. Feinberg, *Freedom and fulfilment: philosophical essays* (1992) Princeton, NJ: Princeton University Press 76–98.

that decision would foreclose the child's future autonomy. Indeed, in English law it may amount to a battery to disrespect a competent adult's current autonomous decision on the basis of the protection of future autonomy.<sup>97</sup> Thus, in English medical law autonomy, as protected by the requirement of consent, is not conditional on substantive notions of rationality. Indeed in *Re T* Lord Donaldson said:

'An adult patient who...suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered. This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.'<sup>98</sup>

This opinion has been repeated with approval on many occasions.<sup>99</sup> However, although English medical law explicitly stipulates that the law will respect a decision as autonomous even if the individual has no reasons for his or her decision, Morgan and Veitch argue that despite express statements to the contrary, in the context of medical law, the courts do actually require that patients demonstrate to the satisfaction of the court that they have reasonable reasons for their decision before they will deem that decision rational and therefore autonomous.<sup>100</sup> They argue that despite the fact that the English courts have repeatedly said that in the context of medical treatment the patient's right to choose or to refuse treatment is not limited to decisions which others might regard as sensible, it exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent,<sup>101</sup> the assessment of mental capacity and the nature of patients' decisions merge, so individuals must, in fact, explain the reasons for their decisions.<sup>102</sup> They focus on the case of *Re B (Adult: Refusal of Medical Treatment)*<sup>103</sup> to argue that, in order to justify her choice, Ms B had to speak of her decision and the reasons behind it. Effectively, in the absence of a decision which would objectively be regarded by others as rational in and of itself,<sup>104</sup> Ms B had to prove to others, in particular the court, that the reasons for her decision were rational. Ms B had to talk of her situation and the level of suffering she was experiencing and convince others that, within the context of her suffering, reasons existed upon which a rational decision to pursue the end of her life could be formed. In essence, the fact that she has reasonable reasons for an apparently irrational decision overrode initial doubts about the rationality of her apparently odd decision and led the court to respect her decision as autonomous, on the basis that it was rational because of the reasons behind it.

97 *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 FCR 1, where an award was made for the battery which occurred when Ms B received medical treatment which was against her wishes.

98 *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 Lord Donaldson 102.

99 See, for example, *Re MB (Medical Treatment)* [1997] FLR 426, Butler-Sloss

100 D. Morgan and K. Veitch, 26 (2004) 'Being Ms B: B, Autonomy and the Nature of Legal Regulation' *Sydney Law Review* 107.

101 See, in particular *Re T (Adult: refusal of treatment)* 1993 Fam 95, Lord Donaldson, 102; *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital and Others* 1985 AC 871, Lord Templeman, 904; *Re MB (Medical Treatment)* [1997] 2 FLR 426, Butler-Sloss LJ, 432.

102 D. Morgan and K. Veitch, 26 (2004) 'Being Ms B: B, Autonomy and the Nature of Legal Regulation' *Sydney Law Review* 107.

103 *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 FCR 1.

104 Because it was a decision which rejected medical advice and would result in death.

Thus, like Dworkin, in ensuring the protection of autonomy, the English courts are concerned that medical decision-making is the result of rational procedure, in that decisions are voluntary and that the individual can show that he or she has reflected on his or her decision and accepts the motivation for it, rather than on preconceived end points which rationality might dictate.<sup>105</sup> Thus the rationality of medical decisions in English law is assessed by the criteria of rational procedure as opposed to a particular end point which might be demanded on the basis of substantive rational values (the way decisions which would lead to the end of one's life might be difficult to describe as rational from the sanctity of life perspective). Given that substantive, as opposed to procedural, rationality is not a condition of autonomous medical decision-making in English law, it might seem odd for the courts to rely the substantively rational value of universal acceptance of relevant information to argue that a person's decision not to know genetic information about him or herself is not autonomous. Indeed, currently the law would not enquire into the rationality of a subsequent decision made on the basis of the unwanted information in determining its autonomy. Given this it might seem awkward if the law thought it necessary to enquire into the rationality of the decision not to have the information before they would deem that decision autonomous.<sup>106</sup> From this perspective, the idea of rationality as a condition of autonomy which is more likely to be acceptable to the law in the realm of genetic information disclosure is procedural rationality rather than substantive rationality. It would follow that, where an authentic and procedurally independent decision to refuse genetic information is ignored, the individual's interest in autonomy is interfered with.

If negligence were imbued with recognition of breach of autonomy as harm, it would follow that health professionals are under a duty not to breach the interest in autonomy via the disclosure of expressly unwanted genetic information.<sup>107</sup> Furthermore, as part of health care professionals' duty to protect autonomy, it is arguable that they have a corresponding duty to take full advantage of a person's capability to be autonomous.<sup>108</sup> Indeed such a duty is imposed on a health professional seeking to obtain consent from a person whose capacity is in doubt in the Mental Capacity Act 2005.<sup>109</sup> It might be argued then that, where possible, health professionals are obligated to raise the profile of unknown genetic unknowns so that people have the chance to know that there may be a relevant unknown and therefore exercise autonomy in deciding whether or not to know what remains unknown.

## Conclusion

In considering when the interest in not knowing genetic information might be justified on the basis of autonomy, this article has distinguished between unknown unknowns

105 D. Morgan and K. Veitch 'Being Ms B; B, Autonomy and the Nature of Legal Regulation' (2004) 26 *Sydney Law Review* 107.

106 This is based on the premise that the decision to refuse the information is made with sufficient information. In each case we assume that the person has the information required to make an autonomous decision. In this case why should decisions to refuse information be assessed on the basis of rationality but not decisions to refuse treatment based on that information? Both have the potential to lead to the limitation of autonomy in the future because of a diminishment of the ability to be self-determining in relation to future decisions.

107 A deep examination of how the legal duty of care might function in this context can be found above at p 3-7.

108 Thank you to Dr Mark Taylor for raising this point.

109 s 1 (3).

and known unknowns. With regard to the former, where there is no opportunity to be self-determining with regard to the receipt of relevant genetic information, it is argued that only disclosures of relevant unknown information can be justified on the basis of autonomy. This is because the opportunity for self-determination has not arisen, so no choice can be made prior to disclosure. Autonomy justifies disclosure because this maximises future opportunities for self determination where contemporaneous self-determination is impossible.

However, where an explicit wish not to know has been made, the imposition of a duty not to disclose can be justified on the basis of autonomy. Where the decision is authentic and procedurally independent such that it represents an exercise of self-determination, the fact that the decision is a refusal of information which might negate future self-determination does not mean that the decision is not autonomous. It is only if autonomous decisions are conditional upon substantive rationality, in that they are required to accept rather than refuse relevant information, that refusals cannot be justified in the basis of autonomy. This is the kind of rational autonomy that Harris and Keywood and Rhodes rely on to deny that autonomy can support a refusal of information about oneself. However, English law does not adhere to this conception of substantive rational autonomy. As long as the relevant procedural requirements regarding understanding and absence of undue influence are present, English law allows people to autonomously restrict their autonomy. Given this, English law is capable of recognising decisions to refuse genetic information as autonomous, even when they concern relevant information. However, as argued here, the law would have to take the significant step of recognising interference with autonomy as harm<sup>110</sup> if it were to provide a remedy for explicitly unwanted disclosures of genetic information in the tort of negligence.

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110 It might be possible to bring a claim which would currently be recognised if one suffered medically recognised psychiatric harm because of the disclosure of the unwanted information.

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