IGNORANCE, INFORMATION AND AUTONOMY

ABSTRACT. People have a powerful interest in genetic privacy and its associated claim to ignorance, and some equally powerful desires to be shielded from disturbing information are often voiced. We argue, however, that there is no such thing as a right to remain in ignorance, where a right is understood as an entitlement that trumps competing claims. This does not of course mean that information must always be forced upon unwilling recipients, only that there is no *prima facie* entitlement to be protected from true or honest information about oneself. Any claims to be shielded from information about the self must compete on equal terms with claims based in the rights and interests of others. In balancing the weight and importance of rival considerations about giving or withholding information, if rights claims have any place, rights are more likely to be defensible on the side of honest communication of information rather than in defence of ignorance. The right to free speech and the right to decline to accept responsibility to take decisions for others imposed by those others seem to us more plausible candidates for fully fledged rights in this field than any purported right to ignorance. Finally, and most importantly, if the right to autonomy is invoked, a proper understanding of the distinction between claims to liberty and claims to autonomy show that the principle of autonomy, as it is understood in contemporary social ethics and English law, supports the giving rather than the withholding of information in most circumstances.

KEY WORDS: autonomy, ignorance, information, rights

Human beings have a schizophrenic attitude to information. On the one hand many believe, with Socrates, that the unexamined life is not worth living and put a high premium on self-awareness and self-knowledge. Others, equally righteously, believe that ignorance is bliss and that the dreams of sleeping dogs should be untroubled by awkward facts. Socrates and the ostrich are the icons of these opposed viewpoints.

In medical practice from the earliest times the need for honest information and the ethics of information giving have been central. Where it has been accepted that information should be withheld from patients, the rationale for so doing has been seen in terms of the obligation of doctors not to harm their patients rather than in any entitlement that the patients may have to shield themselves from unpleasant truths. This seems no longer to be the case, the right not to know, or as we would prefer to term it – the right to remain in ignorance is finding increasing favour. The ostriches are on the march! The United Kingdom *Human Genetics Commission* in its recent consultation document [1] puts the matter thus:

The argument in favour of a right not to know is based on the autonomy of the individual. The desire not to know whether one is at genetic risk of developing a particular condition may be a strong one, and it may be that the individual concerned feels that genetic knowledge would bring with it an unacceptable degree of anxiety about the future, particularly where there is no treatment available for a particular condition. If a person has decided that it will be better not to know, for example, that he or she has a heightened chance of developing a life-threatening disease, then that decision must be respected, even if the person in question could do something to avert the onset of the disease.¹

The right to remain in ignorance of information about oneself has also gained recognition in international legal instruments such as the European Bioethics Convention. Article 10(2) of that Convention 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.²

Further, Takala and Gylling [2] have argued that:

As long as people whose genes deviate from those of the average individual are likely to face suspicion and discrimination, societies cannot legitimately force people to know about their genetic composition.

These statements are illustrative of a number of highly problematic claims that are made in connection with autonomy and the 'right' to remain in ignorance. We argue that there is no basis in law or ethics for a right not to know, whether allegedly derived from autonomy or indeed from any other principle, which 'trumps' all competing claims. Further, we suggest that if a request not to be given medically relevant information, including genetic information, is to be respected, the arguments for according such respect will usually be in terms of the best interests of the individual making the request or on whose behalf the request is made. But these claims of 'best interests' will have to be balanced, not only against claims in similar terms made by others to make known the information, but also against other established rights or interests which will include claims to free speech and respect for autonomy.

In this paper we offer a critique of arguments located in ethics and in law which seek to defend a 'right' to remain in ignorance. By a 'right' in this context we mean an entitlement which others must respect not simply because the balance of the moral, legal or political argument indicates that this is the right thing to do but because this entitlement, in Ronald Dworkin's terms, somehow trumps other claims and must in virtue of its status as a right be accorded enhanced and often overriding respect [3]. We premise our discussion of the legal claim to ignorance primarily on the law of England and Wales for two reasons. The first is pragmatic, in that it is the jurisdiction with which we are most familiar. Secondly and more importantly, however, it is a legal system whose jurisprudence is undergoing

an important transition in order to accommodate the recently incorporated rights contained in the European Convention on Human Rights.³ Whilst ethics strives to investigate, and in the present case, challenge the ontological foundations of a 'right' to ignorance, the English common law system is struggling to reorient its jurisprudence to ensure the recognition of rights such as the right to respect for one's private and family life and the right to freedom of conscience and expression. Our survey of legal and ethical discussion makes clear that the claim that competent individuals are the best interpreters of their own best interests is powerful, but this does not amount to an unassailable right nor to an entitlement to be ignorant of one's health status. Whilst it is crucially important that we recognise the dilemmas and difficulties involved in the decision whether or not to undergo genetic screening, for example, and whether or not to know its results, this should not lead us readily to commend the recognition of a 'right' not to know. Equally, the presumption that parents are the foremost guardians of the best interests of their children and that those interests *require* that parents and children remain ignorant of some medical facts about the children, particularly information about life expectancy and late onset disorders, is not what we believe sustainable.

A PATIENT'S 'RIGHT' TO IGNORANCE DERIVED FROM AUTONOMY?

The value of autonomy finds its legal expression in the law of consent. Cardozo J.'s now classic statement in the case of *Schloendorff v. Society of New York Hospital* (1914) 211 NY 125,⁴ has shaped English juridical thinking on the law of consent. In *F v. West Berkshire Health Authority (Mental Health Act Commission Intervening)* [1989] 2 All ER 545, the House of Lords considered whether it would be lawful to sterilise an adult woman with intellectual impairments and what the impacts of such practices would be for patient autonomy. Lord Goff, at p. 864, explained that patient autonomy or self-determination entitles those patients who are (unlike patient F) mentally competent, to make decisions about their care, even though such decisions may lead to their death:

... it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that, if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so.

A normal and reasonable presumption about the relationship between information and autonomy, indeed one adopted by the House of Lords

in the case of *Re F*, is that the exercise of patient autonomy is contingent on the ability to understand relevant information and on the receipt of such information. Thus, the emphasis on 'information' in the now almost universally accepted doctrine of informed consent.⁵ In ethical terms, consent and the autonomy that it protects is vitiated to the extent that it is ill informed [4, chapter 10]. In legal terms, the provision of information is crucial to enable patients to make meaningful decisions about their future care and well-being, such that failure to provide information concerning risks inherent in medical treatment and the availability of alternative treatments are actionable in English law through the tort of negligence. Furthermore, failure to provide information relating to the nature of any proposed intervention will invalidate patient consent and give rise to an action for battery before the civil or criminal courts.⁶

Of course, all information unwillingly received violates any alleged 'right' to remain in ignorance. We suggest, however, that such a right cannot easily be defended by reference to claims to autonomy. Let us begin by acknowledging that all decisions are irrevocable in the sense that time is irreversible. Every choice, including a choice to omit procedures, impacts on autonomy to some extent, even though we may not question the legitimacy of our choice. Where choices are made for others, the question of the legitimacy of such a decision always arises. To suggest, however, that such choices, made for others or for ourselves, disregard autonomy is to make a different claim; it is to claim that such choices somehow either *reduce* autonomy, or are *inimical* to liberty rights or claims that the individual may have or may come to have or make. This is a complicated claim, partly empirical and partly theoretical. To assess its force we must first remind ourselves that all choices we make for ourselves, our children and others not competent to choose for themselves, pre-empt and foreclose other decisions we might make or options we might exercise. If an adult agrees to be tested, for example, this removes the option not to have been tested. If she decides not to be tested, she is denied the option to 'benefit' from (or 'live in the light of') the results of that test. Autonomy here walks both sides of the street. This argument applies to children and to competent adults in slightly different ways.

Autonomy and Competent Adults

If I discover that I am carrying gene X, which means I have an increased risk of developing condition Y, my autonomous decision-making shifts to making choices about my future care in the light of this knowledge. Effectively, I have been deprived of the opportunity to make decisions that I otherwise might have made. Similarly, if I decide not to be tested for gene

X, my autonomous decision-making becomes oriented to making choices in the absence of this knowledge. In either scenario we can argue that our decision-making is affected by our choice to know or not to know about our medical/genetic status. However, this, of itself, does not establish that our autonomy has been adversely affected by knowing something we would prefer not to have known.

Autonomous compromise of autonomy

If the patient has expressed a preference not to know certain information about her health status, could this be said to constitute the exercise by an autonomous agent of the 'right' not to know? If the patient has signalled to the doctor that there is information that s/he does not wish to know about her health status, the nature of a forthcoming medical procedure, its risks, side-effects or the availability alternative therapies, is the doctor under a duty to respect this autonomously expressed information preference? Failure to respect someone's choice only compromises his or her autonomy where the choice was autonomous. Thus if I frustrate a suicide attempt where I have good reason to believe the attempt was made by 'a mind disturbed' to the extent that a genuine wish to die was absent, I do not necessarily violate the autonomy of that individual.⁷ Equally where I give someone (against their will) reliable information about themselves or their condition which is relevant to decisions they must make I may violate a liberty they assert but I do not violate their autonomy, for the information I give them is necessary for their autonomous decision making.

Now it might be claimed that it is possible autonomously to deny oneself future autonomy. In the trivial sense already noted this is necessarily true, since all choices foreclose other choices, but are there other legitimate cases of autonomously chosen restrictions on autonomy? Of course there are, but a distinction must be drawn between autonomously chosen restrictions on autonomy which are consistent with autonomy understood as an ethical principle and such choices which are inconsistent with autonomy. If I choose to enter a monastic order or to join the armed forces or the police, I accept that my choices will be limited by the rule of the order or the discipline of the service in question. These are in a sense fully autonomous restrictions on autonomy. We say 'fully autonomous' because although I agree to be bound, still I am free to choose. I may always leave the order or the service or refuse an order given by my superiors. As discussed by Osiel [5], Nuremberg confirmed the legal force of this philosophical truth by denying that superior orders absolved individuals from autonomous choice, nor did it rob them of the ability to resist superior orders even when they had taken an oath to obey.

However, there are cases in which people do purport to autonomously surrender autonomy. Those who would sell themselves into slavery are a paradigm case. Here although the sale may be a contract freely entered into and hence 'autonomous' as a choice, it is a choice inconsistent with the idea of autonomy and hence not a choice that is protected by appeals to autonomy as a moral principle. Those who deny others the right to sell themselves into slavery do not therefore violate their autonomy.⁸

Suicide

Suicide may apparently also be a case of an autonomously chosen path which is inconsistent with the idea of autonomy in that it forecloses all capacity for autonomous choice in the individual. To see whether or not this is in fact so we need to remind ourselves of the point of valuing liberty – freedom of choice. The point of autonomy, the point of choosing and having the freedom to choose between competing conceptions of how, and indeed why, to live, is simply that it is only thus that our lives become in any real sense our own. The value of our lives is the value we give to our lives. And we do this, so far as this is possible at all, by shaping our lives for ourselves. Our own choices, decisions and preferences help to make us what we are, for each helps us to confirm and modify our own character and enables us to develop and to understand ourselves. So autonomy, as the ability and the freedom to make the choices that shape our lives in accordance with our own conceptions of what that shape should be, is quite crucial in giving to each life its own special and peculiar value [6].

Concern for welfare, and the paternalist control it is so often used to justify, ceases to be legitimate at the point at which, so far from being productive of autonomy, so far from enabling the individual to create her own life, it operates to frustrate the individual's own attempts to create her own life for herself. And of course this also applies in the limiting case of suicide or of course to voluntary euthanasia, where the individual's attempts to create her own life involve creating its ending also. This is why voluntary euthanasia and suicide are consistent with the idea of autonomy. They are part of the attempt to create a life which is authentic to the individual, shaped by that individual and not subject to distorting pressures from without. An end to her life chosen by the individual liberates her from distorting pressures that deny her the freedom to shape her own life so far as this is possible, including the creation of its finale. This is why suicide is quite unlike slavery. In slavery the life is shaped by others including very often its ending. Autonomy is not simply the exercise of choice but of control – literally self government. The suicidee is in control, is self governing, shaping her own life in a way that the slave is not.

How does denial of a claim to ignorance fit?

It is now easy to see how absence of crucial information is inimical to self government, to the ability to control one's own destiny, and hence inimical to autonomy. Ignorance of crucial information is inimical to autonomy in a way that other autonomy-limiting choices are not. For 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. If I do not know that my life is only likely to last five more years, rather than say twenty five more, many of my priorities will be inappropriate and some will be self-defeating. Of course it is not necessarily irrational not to want to know one's probable life expectancy and many would be prepared to forego autonomy rather than face the knowledge of a looming premature death. However they cannot defend the wish to remain ignorant of a fact like that in the name of autonomy.

What of those who have not asserted a right to remain in ignorance?

We must also consider that discussion of a 'right' not to know information about our health status has extended to those people who do not currently know about their health status but have not made a choice to remain in ignorance. In other words, they have exercised no waiver of health care information.⁹ For such patients, the conceptualisation of a right to ignorance premised on autonomy is surely also problematic. If information is regarded as a precondition for the exercise of autonomy, then any suspension of information relevant to autonomous action inevitably precludes the ability to act autonomously, for it has been noted that "[a]n autonomy analysis . . . does not permit us to respect a person's state of non-knowledge. Autonomy requires choice and choice requires information through disclosure" [8, p. 189].

In legal and ethical circles there is considerable debate about the nature and amount of information necessary for autonomous action. The law on information disclosure serves two related functions. It provides guidance to doctors concerning the lawful discharge of their professional obligations to the patient. Furthermore, it acts to ensure that patients receive sufficient information to enable them to exercise informed choices about their care. Significantly, however, English law recognises that patient autonomy is not sufficiently eroded to vitiate patient consent even when information has been withheld concerning the availability of alternative treatments or the side-effects inherent in a particular treatment. Failure to provide such information, however, can give rise to an action in negligence.¹⁰ The question for the courts is whether the withholding of this information

constitutes a breach of the doctor's duty of care to the patient and further whether any breach impacted detrimentally on the patient's health care decision-making by leading her to make a decision that she would otherwise not have made. In recent years, English law has recognised that the scope of a doctor's duty of disclosure of risks inherent in medical treatment will be determined by reference to what a reasonable person in the patient's position would want to know.¹¹ If the information would ordinarily be solicited by the 'reasonable patient' then the onus would appear to fall on the doctor to establish that his/her patient deviates sufficiently from the reasonable patient to justify withholding certain information. English law's conceptualisation of patient autonomy, particularly in recent years,¹² indicates that there is a strong presumption in operation that the 'reasonable patient' would wish to know, rather than not know, information about their health status. Support for this default position can be found from judicial dicta in the series of cases where patients have alleged negligence on the part of health professionals who failed to inform them of risks and side-effects inherent in medical procedures that they agreed to undergo. In the House of Lords decision of *Sidaway v. Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital and Others* [1985] AC 871, Lord Bridge's speech (at p. 900) makes the important connection between the professional obligation of information disclosure and the exercise of patient autonomy:

... a decision as to what degree of disclosure of risks is best calculated to assist a particular patient to make a rational choice whether or not to undergo a particular treatment must primarily be a matter of clinical judgement.

Thus, patients should be provided with an appropriate level of information to enable them to operate as rational 'choosers' in their encounters with health care personnel. Furthermore, the law on mental incapacity supports disclosure of information to patients, in order to assess a person's ability to function autonomously. English law presumes every adult of sound mind to be capable of acting autonomously and of making legally effective decisions about her health. That presumption will be displaced if the patient is unable to understand, retain and believe¹³ relevant information, and to weigh it up, *balancing risks and needs* in order to arrive at a choice.¹⁴ A test of mental incapacity, such as was endorsed by the High Court in *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819, requires an assessment of the patient's ability not just to understand that information which would enable her to give a legally effective consent to treatment (i.e. information relating to the nature and purpose of the procedure), but also additional information concerning the risks involved. A sensible reading of the court's judgment in *Re C* would suggest that this

additional information concerning risks involved in the procedure should be provided to the patient as a matter of good practice in order for a reliable assessment of the patient's capacity to take place.¹⁵ Further support can be drawn from the recent case of *R v. St George's Healthcare NHST Trust, ex parte S* [1998] 3 All ER 673, in which the Court of Appeal provided guidelines on how the courts should proceed when faced with an adult patient who refuses consent to medical treatment. Judge L.J. stated that any hearing before the court should take place after the judge has been provided with all relevant information. This, he suggests (at p. 704), should include not only information relating to the reasons for the treatment, but also the risks involved in it and information as to why the patient is refusing the treatment. Such information is necessary in order for the judge to reach an 'informed conclusion' about the patient's capacity. If the judge is to be furnished with such information, it would seem illogical and inappropriate to deprive the patient of the same. Thus, a patient's ignorance about her health status does not exempt health professionals from their legal duty of disclosure of information, whether that information relate to the nature of the procedure or to the inherent risks and side-effects or the availability of alternative treatments.

Autonomy and Children

A child's future autonomy interests?

An important argument made in relation to a child's 'right' not to know concerns the removal of the possibility of the child making his or her own decision whether to undergo medical treatment at a future time. In the context of genetic testing, it has been said, for example, that "testing during childhood removes the individual's future autonomy and confidentiality, and may cause damage to their self-esteem and future interpersonal relationships" [10].

Any supposed 'right' of children to make up their own minds about having such a test when they are older, must, however, be balanced against claims that the failure to test deprives children of the 'right' to grow up in an atmosphere of openness and understanding of their situation and a 'right' or interest not to form unrealistic hopes and plans about the future. These might include the right to make informed plans and decisions about:

1. Rational education prospects (how long a period of preparation for a career would be rational?)
2. Rational career prospects
3. Rational marriage plans
4. Rational timing of children

This is not to say that it is obviously in a child's interests to be tested. Indeed, there may be situations when testing is manifestly contrary to a child's best interests. The point to be made, however, is that such interests cannot be determined solely by reference to a child's autonomy interests.¹⁶ Such cases raise real questions about where the balance of a child's best interests lie and consideration must be given to factors other than autonomy that may determine whether a child's medical/genetic status is to be known.

One clear conclusion here is that there is no sense in which a decision not to test children, even for late onset conditions, protects their autonomy whereas a decision to test violates it. Again autonomy walks on both sides of the street and any such decisions must be based on a calculation of the best interests of the child and on whether or not there are sufficiently powerful and clear grounds to override the parents presumptive claim to be the guardian of such interests.

What's best for children?

If decisions must be taken on behalf of children, the presumption must surely be that health screening is primarily a matter for parents. This and most societies operate rightly with the view that unless and until it can be shown that the presumption that parents are the best guardians of their children's interests must be overturned in order to protect children from serious harm, decisions about most things concerning children should remain with parents.¹⁷ Thus, the English Court of Appeal has acknowledged that in decision-making about children's health and welfare, where there is genuine scope for a difference of view as to the child's best interests,

there must be a likelihood (though never of course a certainty) that the greater the scope for genuine debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature.¹⁸

When there are conflicts between parents and health care professionals as to where a child's interests may lie, the courts intervene to offer an independent assessment of a child's best interests. In the case of childhood testing for presently untreatable conditions, interests seem to be sufficiently finely balanced to make the overturning of the presumption in favour of parental decision-making improbable and implausible. Where screening would permit early medical intervention that would have the effect of improving the child's condition, however, there are legal arguments to suggest that such testing will outweigh any parental wish to remain in ignorance or any future autonomy interests of the child [13].

In the case of *Re C (HIV test)* [1999] 2 FLR 1004, the London Borough of Camden applied to the High Court for permission to have a 5 month-old baby blood-tested for HIV. Both parents opposed the testing of baby C, expressing doubts over the conventional understanding of HIV, its causes and appropriate treatment. C's mother was aware of her own HIV positive status prior to C's conception and had declined to follow medical advice aimed at reducing the risk of transmitting the virus to her baby.¹⁹ Following unresolved discussions between the parents, health care staff and local authority personnel, the local authority applied to the court to have the baby tested for HIV.²⁰ In granting the order requested, Justice Wilson was firmly of the view that C's best interests could only be served by the performance of the test, given that prophylactic medication could be administered if the baby were found to be HIV positive, or that measures could be taken to prevent the baby from becoming so infected if found to be HIV negative.²¹ Explaining that the parents "... cling to their theories with the intensity of the shipwrecked mariner who clings to the plank of wood", his Honour was clear that their claim to ignorance must yield to an objective assessment of the child's best interests. Lady Justice Butler Sloss in the Court of Appeal dismissed the application for permission to appeal and suggested that parental ignorance about a child's health is necessarily contrary to a child's best interests.

Whether such an approach will be followed in cases where medical screening will do little to improve the child's health remains to be seen. It is clear, however, that any interests that the child or its parents have in remaining ignorant of the child's health status will yield, in law, to countervailing measures that prevent harm to the child or promote the child's well-being or both. It is true that to raise a child in the knowledge that he or she will develop a dreaded familial disease, may cause additional harm but there is no reason to assume that this must be so. Unless there is strong reason to suppose that serious harm will result, which we doubt, the principle of non-maleficence cannot be invoked. The psychological impacts, for example, of being informed of a familial disease are contested [14, p. 122]. Furthermore, it should be noted that even where the principle of non-maleficence is appropriately invoked, that is where disclosing information about the child's health status is likely to do more harm than good, it is always a further and separate ethical question as to whether disclosing information which is against the child's interests is wrongful. Many people believe that bringing children up in a religion, for example, is strongly against the child's interests, but it does not follow that this practice must be prevented. Equally, many compromises with an individual child's best interests are imposed by the constraints of family life. It may not be in

Billy's best interests to go to the same school as his elder sister Beatrice, but if the school that would best serve his interests is too far away to be conveniently accessed, or too expensive, the economy and convenience of sending both children to the same school may be a justifiable departure from Billy's self interest.²² Undoubtedly, decision-making over the health screening of children must be examined closely and careful scrutiny of the potential harm to the child must be assessed, but the harm that may result in testing a child or disclosing information about the child's health status must also be weighed against other interests. These will include the child's strong interest, already noted, in not being encouraged to form unrealistic expectations about its life and the parent's needs to make realistic plans for the child including financial and care planning for the onset of illness, some of which are further discussed below. English law is clear, however, that in making this assessment any interest parents may have in remaining ignorant of their child's health is not a relevant consideration.²³ So while we believe that the presumption that parents are the right people to make such decisions for their children is strong, if such a presumption is ever to be defeated, it is likely that the weight of both the ethical and legal arguments for defeating such a presumption will lean towards provision of information rather than acquiescence in refusal.

A RIGHT TO IGNORANCE AS A LIBERTY CLAIM?

If, as we suggest, the right to remain in ignorance cannot be justified by claims to autonomy, it might be based on a simple claim of a right to liberty where liberty includes the right to make free, but non-autonomous decisions or autonomous but autonomy-limiting, decisions.²⁴ This is still a powerful right or entitlement, but like all liberty claims it is defensible in its strongest form only where the exercise of liberty is compatible with the exercise of a like liberty for all – where it does not result in significant harm to others or indeed compromise comparably important rights or liberties possessed by others. Where the information relates also to the genetic constitution of others, my 'right' not to know must be weighed against family members' entitlements to make their own free choices about access to the information. Inevitably in the context of genetic diseases, if patient A is tested and discovers information about her genetic status, this will inevitably disclose information about the health status of those to whom she is genetically related.

Just as liberty claims fail when they are incompatible with a like liberty for all, this incompatibility reveals a clear incoherence in the idea that protection from unwanted information preserves autonomy. Suppose you

know that I am HIV positive but I do not (you are a doctor and a lab mistakenly ran an HIV test on a blood sample of mine in addition to other tests and has given you the results). I do not want to know my HIV status because I want to preserve my autonomy with respect to decisions as to whether to continue to have unprotected sex with my nineteen current partners and I know I am not so vicious as to knowingly put them at risk. Should you ignore my claim to a right to remain in ignorance? Note two features of this example. The first is that it is an illusion that ignorance preserves autonomy here. I, by hypothesis, do not want to endanger my partners, remaining in ignorance is thus self-defeating, it frustrates an autonomously chosen objective that I have, and so far from protecting my autonomy of action it defeats it.²⁵ The second is that your ethical duty to protect others (including my partners) is, as we have noted, at least as strong or stronger than your duty to respect my preferences about disclosure.²⁶

In ethics then my right to tell the truth, including truths about you, is at least as strong as your claim not to hear it. Just as I may tell you that, for example, you are offending others even though you don't wish to hear any such thing, I may also tell you that you have particular genetic mutations, or indeed have a terminal illness, if either I judge that it is important for you to know or because I judge that your failure to receive such information will harm others, including the medical team that would otherwise have to bear the responsibility of decisions about you themselves.²⁷ Of course I may be wrong in my judgement or my calculation of the harm-benefit equation. But it is clear, surely, that you have no right or entitlement to pre-empt my judgement of where the balance of harm-benefit and even morality lies.

In this regard, English law parallels the ethical arguments. The Data Protection Act 1998 provides the framework in English law for people's access to personal data held by others. Section 7(4) acknowledges that a health professional may provide information to a patient who wishes to have access to information stored on his or her medical record. The fact that that information may disclose information about a third party (a relative or other) who does not wish that information to be disclosed will not, by itself, render the disclosure unlawful. In such instances, the health professional must make an assessment of whether it is reasonable in the circumstances to comply with the patient's request for information, taking into account, *inter alia*, the third party's preference not to have the information disclosed. It is here then, that the competing liberty claims will be weighed in the balance. The Data Protection Act 1998 affords no right of veto, no absolute right to ignorance in these circumstances.²⁸

Similarly, English law on patient confidentiality fails to support any supposed right to keep others in ignorance of one's health status, requiring once more an evaluation of competing liberty claims. The legal duty of confidentiality is said to uphold the patient's right to self-determination in deciding what information should be disclosed and to whom.²⁹ The disclosure of confidential information is permitted, provided that there exists some lawful authority for the disclosure. In the case of adults capable of making their own health care decisions, lawful authority will be provided by the patient's consent. Where the patient is a child, lawful disclosures of information may take place in the child's best interests. Given that autonomy arguments in support of a right of ignorance are difficult (if not impossible) to sustain, it is hardly surprising that the obligation of confidentiality sits ill at ease with any claimed right to ignorance.

In English law the remedy of breach of confidence provides patients with legal redress when health care professionals have failed to respect confidential information. It has been noted, however, that the obligation of confidentiality fails to recognise in all circumstances the primacy of patient autonomy. Indeed, there will be no breach of confidence where the patient's interest in keeping information confidential from others, including relatives, is out-weighed in the balance by broader 'public interest' considerations. For example, broader public interest concerns (including for example the prevention of serious harm to others)³⁰ may well outweigh those interests in favour of confidentiality (which include a recognition of the therapeutic importance of maintaining a relationship of trust between practitioner and patient).³¹ Once again, the interests that family members may have in wishing to know my health status will have to be weighed in the balance against my wish not to have that information disclosed, alongside information concerning the likelihood and potential magnitude of harm to others.

FROM AUTONOMY AND LIBERTY CLAIMS TO PRIVACY AND FREE SPEECH?

Privacy

It has been argued that the right to respect for private life, guaranteed by Article 8 of the European Convention on Human Rights, comprises not just an obligation to keep information known to the patient confidential from others but also compels health care professionals to respect the patient's right not to know information about his health status. Graeme Laurie's development of the concept of 'spatial privacy' advocates that our

“state of separateness from others” be respected and that the benefits of genetic ignorance be recognised in determining whether our right has been infringed [8, 14]. Laurie’s conception of a spatial privacy right acknowledges the inadequacy of concepts such as confidentiality and autonomy to support a ‘right’ to ignorance, given that patients may be seeking not to prevent disclosure to others, but rather to themselves and given that arguments in favour of a right to ignorance derived from autonomy fail to acknowledge that the state of non-knowledge is potentially valuable to patients [14, p. 126]. A right of medical or genetic privacy would, of course, be subject to countervailing public interest concerns which may ‘trump’ the desire to remain in ignorance about our health status. Thus, the right to respect for one’s private life, protected by Article 8 of the European Convention on Human Rights, recognises that the enjoyment of that ‘right’ must be weighed in the balance against broader public interest considerations stipulated by paragraph 2 of that Article. It will not be a breach of Article 8, for example, if disclosure of information is necessary in a democratic society for the protection of the rights and freedoms of others or the protection of health or morals.³² Whilst the European Court of Human Rights has recognised that the unsolicited disclosure of information about our health status constitutes an interference with our enjoyment of that right, the circumstances in which our enjoyment of that right will yield to other public interest concerns reminds us that the right is not absolute.³³

For those advocating a right to remain in ignorance, the development of concepts such as spatial privacy may be a tempting, though not unproblematic foundation for genetic ignorance. Indeed, it seems that English law may not be far away in its recognition of such a right.³⁴ In *Douglas v. Hello! Ltd* [2001] E.M.L.R. 9, a case concerning the unauthorised publication of wedding photographs of Michael Douglas and Catherine Zeta-Jones, the Court of Appeal have given the strongest indication so far that English law is prepared to recognise a ‘right’ of privacy. Such a right, according to Sedley L.J. (at p. 234) comprises a right to “some private space”, free from the unjustified interference of others. Whether an unsolicited disclosure of information about a person’s health status will be considered to be a breach of a right to privacy will, of course, depend on a number of factors, not least consideration of the treatability of the patient’s condition and the competing interests of others potentially affected by the disclosure, including the interests of the patient’s relatives and also the interests of health professionals.

It may be that cases attempting to assert a right to genetic privacy, where the health and perhaps the very lives of third parties hang on the result, may well be interpreted differently by the courts. In *Douglas v. Hello!*

it could be argued that it was not really privacy that was at issue since the Douglasses had sold their 'privacy' to a rival magazine, but exclusivity – the entitlement to dispose of their privacy to whom they chose for a particular consideration. Countervailing interests, such as the commercial interests of the rival magazine, were not sufficient in that case to over-ride the rights of the plaintiffs and justify the granting of an injunction. We suggest that a 'consideration' of equal or greater ethical and legal weight may well justify disclosure to the patient or to relevant third parties.

There remains, however, a more fundamental objection to a right to remain in ignorance premised on a legal or ethical right to privacy. It is true that the privacy rights have emerged in order to protect the liberty of subjects from encroachment by state agencies and private bodies.³⁵ But liberty in the sense of freedom from physical, legal or intellectual constraint is regarded as valuable because we recognise the importance of allowing each person the freedom to fashion for themselves a life-style, a value-system, a physical space, which is protected by law. There are many possible foundations for the right to privacy – autonomy, dignity, physical and moral integrity – indeed, the European Court of Human Rights has made reference to all of these whilst at the same time declining to limit the scope of the right by laying down the foundational parameters of the right.³⁶ Whilst the scope of privacy is indeed broad, it is difficult to argue that ignorance, a state of non-knowledge, is instrumental in the furtherance of any of the values that underpin the right to privacy. Further, the assimilation of intellectual space with physical space in the formulation of the concept of spatial privacy is problematic if we seek to argue that occupying our intellectual space entitles us to be ignorant of that space, its parameters or the claims of those who might seek to enter it. A state of non-knowledge, we suggest, is not consistent with the right to respect for one's private life and in some instances, the claim is self-defeating.

Autonomously to assert an entitlement to non-interference with my intellectual space surely demands that I have reflected on that which I do not want to know, and am therefore of course no longer ignorant. If I have reflected on my own position and contemplated my intellectual space, yet nevertheless inform health professionals that I do not wish to know certain information about my health, a right to intellectual privacy may be said to exist insofar as I have sought to waive the disclosure of information. In such cases, the legitimacy of the interference with the claimed right will be determined by weighing in the balance competing claims, such as the rights and freedoms of others. The range of circumstances in which competing claims are potentially to be weighed in the balance against the right to privacy are so diverse and the competing

claims sufficiently compelling, that the right to intellectual privacy, free from unwanted disclosures about one's health status, is unsustainable as a 'right' properly so called. It is not for example clear that my claimed right to privacy 'trumps' a doctor's duty to ensure that it is I who take, and take responsibility for, crucial decisions about my life and health.

Free Speech

One other, perhaps unlikely, ground for rejecting a right to ignorance might be the right or entitlement to freedom of speech or expression protected by many constitutions and by Article 10 of the European Convention on Human Rights. This right, while not much invoked by health professionals with respect to communication with patients might be appropriately called in aid when health professionals are confronted by claims that purport to prevent them from telling patients the truth. It is difficult to see what moral or legal entitlement patients might claim which would be powerful enough to bridle health professionals who wish to present patients with an accurate picture of their health status. Truth is after all a complete defence to charges of libel or slander in English law and the claim or an entitlement to be shielded from 'unsavoury' information about oneself is regarded as inferior to this long-standing common law protection.³⁷ Truth will not always out, however, since the truthful disclosure of information by the media about a court case may, depending on the circumstances, give rise to an action for contempt of court and the dissemination of apparently truthful statements which pose a threat to public order may well fall foul of the law.³⁸ Free speech must be weighed in the balance against competing interests, such as the necessity to protect national security or to safeguard the impartiality of the judicial process. Whilst we cannot then be confident that in the English legal system truth will always prevail, we suggest that recognition must rightly be given to the compelling claims to freedom of expression and professional conscience of health care providers seeking to ensure that their patients are fully informed about their health.

CONCLUSIONS – PASSING THE BUCK

The claim of an entitlement to be shielded from information relevant to one's health status and to future decisions the individual will face places health professionals in a dilemma. The patient is in effect declining to face and take responsibility for decisions about the management of their condition and indeed about their lives which are properly theirs to take. While the desire to abjure responsibility is understandable, and even attractive

in some circumstances, it is less clear that others can be placed under an obligation not only to respect the claim to irresponsibility but to shoulder some of the responsibilities refused by others. For very often the health professional will have to make decisions about patient care (even those which do not require patient informed consent) which properly belong to the patient and which cannot be made by her without divulging the information which has been refused. Here the patient has literally passed the buck to the health professional without so much as a "by your leave". Of course if health professionals are willing to accept this responsibility that is one thing, but if they are not it is difficult to see on what basis this responsibility can be forced on them.

While acknowledging the powerful interest that people have in genetic privacy and its associated claim to ignorance, and noting some equally powerful desires people may have to be shielded from disturbing information, we conclude that there is no such thing as a moral right to remain in ignorance and that any claims to be shielded from information about the self must compete on equal terms with claims based on the rights and interests of others. Moreover there is no support in English law for the existence of any such legal right. This does not of course mean that information must always be forced upon unwilling recipients, only that there is no *prima facie* entitlement to be protected from true or honest information about oneself. In balancing the weight and importance of rival considerations about giving or withholding information, if rights claims have any place, rights are more likely to be defensible on the side of honest communication of information rather than in defence of ignorance. The right to free speech and the right to decline to accept responsibilities to take decisions for others imposed by those others seem to us more plausible candidates for fully fledged rights in this field than any purported right to ignorance. Finally, and most importantly, if the right to autonomy is invoked, a proper understanding of the distinction between claims to liberty and claims to autonomy show that the principle of autonomy supports the giving rather than the withholding of information in most circumstances.

NOTES

¹ This is of course a consultation document and the HGC is not committing itself to any particular view of the matter. Later on the same page (page 19) the document summarises the contrary view presented in this paper. One of the authors must here declare a particular interest in that John Harris is a member of *The Human Genetics Commission*.

² Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and

Medicine 1997. See also the UNESCO Universal Declaration on the Human Genome and Human Rights 1997.

³ The Human Rights Act 1998 requires that judges, so far as is possible, interpret domestic legislation in conformity with the European Convention and its jurisprudence (section 3). In addition, public bodies, including courts, must act in conformity with the rights contained in the European Convention on Human Rights, unless to do so would bring the court in breach of domestic legislation (section 6).

⁴ "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."

⁵ The idea that a competent patient must give fully informed consent before any medical treatment becomes legitimate.

⁶ In the case of *Chatterton v. Gerson* [1981] 1 All ER 257, Justice Bristow explained that "... once the patient is informed in broad terms of the nature of the procedure which is intended, and gives her consent, that consent is real, and the cause of action on which to base a claim for failure to go into risks and implications is negligence, not trespass."

⁷ I do so only if I am wrong in my estimation of their competence.

⁸ Although they do of course frustrate an autonomous choice.

⁹ For a discussion of this point see Bottis [7]. The legal status of information waivers in English law remains to be formally determined by the courts.

¹⁰ *Chatterton v. Gerson* [1981] 1 All ER 257.

¹¹ *Pearce and another v. United Bristol Healthcare NHS Trust* (1998) 48 BMLR 118.

¹² Note for example the shift in the courts' interpretation of the doctor's duty of information disclosure to patients. A doctor's duty to exercise reasonable care and skill in the explanation of risks, side effects and alternatives entails not only that the appropriate amount of information is imparted by her, but that it is communicated to the patient in terms that are intelligible to the patient. See, for example *McAllister v. Lewisham and North Southwark Health Authority* [1994] 5 Med. L.R. 343.

¹³ Note that the separate requirement of 'belief' was omitted in the Court of Appeal's statement of the test of incapacity, though Butler Sloss L.J. acknowledged that some compulsive disorders which stifle belief in the information presented to the patient will render the patient mentally incompetent to make a legally effective decision: *Re MB (adult: medical treatment)* (1997) 38 B.M.L.R. 175.

¹⁴ *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819, p. 822.

¹⁵ This contention is supported by Kennedy and Grubb [9, p. 614], who suggest that "[l]ogically, the capacity or ability to understand 'what is involved' must embrace this further information [relating to risks, etc . . .] since the basis for requiring disclosure is to allow the patient to make an informed choice and this can only be achieved if the patient is able to understand that further information." Note also that a failure to provide this additional information would not and should not render a person unable to provide a valid consent/refusal to medical treatment.

¹⁶ In the recent case of *Re C (HIV test)* [1999] 2 FLR 1004, it is noteworthy that the High Court did not consider as part of its determination of baby C's best interests, the child's autonomy interests. Compelling C's parents to have the child tested for HIV undoubtedly removes the possibility of C deciding at a later date whether to have the test or not, an argument which C's mother put to the court and which was regarded as a "hopeless programme for the baby's protection". The case is discussed further below.

¹⁷ There are also arguments, which assert and defend a right or entitlement to reproductive liberty to the same effect: see Harris [11] and Robertson [12].

¹⁸ *Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502, p. 513.

¹⁹ That advice consisted of taking medication during the last weeks of pregnancy; undergoing a caesarian section and not breast-feeding the baby.

²⁰ The test proposed was the Polymerase Chain Reaction (either on the DNA or the RNA).

²¹ C's mother was advised to stop breast-feeding should the baby test negative for HIV, though Justice Wilson (at p. 1015) refused to contemplate making an order compelling the mother to refrain from breastfeeding: "My belief is that the law cannot come between the baby and the breast. Indeed, if she cannot be persuaded by rational argument that she must curb her instinct to feed, I doubt whether the mother would comply with a court order, which would be, in effect, impossible to enforce." *Op. cit.* p. 1015. At the hearing before the Court of Appeal, for permission to appeal to that Court, it was reported that the parents could not be found and it was feared that they had disappeared to avoid submitting the child to the test.

²² Even where the compromise isn't salvaged by feeding back into the family's welfare in ways that lead overall to the maximization of Billy's interests.

²³ Consider the case of *Re C*, discussed above. Butler Sloss L.J. was clear that the best interests of the child are not to be weighed in the balance against the parents' wish to remain in ignorance. She asks (at p. 1020), "can it be in the child's best interests for the parents to remain ignorant of their own child's state of health? You only have to ask that question for most people to say no. We are not talking about the rights of parents. We are talking about the rights of the child".

²⁴ Like the decision to sell oneself into slavery discussed above.

²⁵ Jørgen Husted [15] seems unaware of the force of this point.

²⁶ There are circumstances where English law will impose a duty to protect others. Consider, for example, the Public Health (Control of Diseases) Act 1984, which compels a registered medical practitioner to over-ride patient confidentiality and inform the local authority of the patient's condition and personal details if the patient is suffering from a notifiable disease (cholera, plague, relapsing fever, smallpox, typhus) or from food poisoning. For a discussion of this legislation, see Brazier and Harris [16].

²⁷ The legal ramifications of this argument are discussed in the section on confidentiality, below.

²⁸ Indeed, earlier legislation which did not permit disclosure without the prior consent of the third party was held to be in breach of the right to respect for one's private life, contrary to Article 8 of the European Convention on Human Rights: *Gaskin v. UK* [1990] 1 FLR 167.

²⁹ It has been noted that the legal duty of confidentiality also meets utilitarian objectives [17].

³⁰ In the case of *W v. Egdell* [1990] Ch. 359, a psychiatrist's disclosure of a confidential report on a patient's mental health and potential dangerousness was held not to be in breach of confidence, for "[a] consultant psychiatrist who becomes aware, even in the course of a confidential relationship, of information which leads him, in the exercise of what the court considers a sound professional judgment, too fear that such decisions [that may lead to the patient's release from hospital] may be made on the basis of inadequate information and with a real risk of consequent danger to the public is entitled to take such steps as are reasonable in all the circumstances to communicate the grounds of his concern to the responsible authorities", p. 424.

³¹ Note Rose J.'s observation that "... Preservation of confidentiality is the only way of securing public health: otherwise doctors will be discredited as a source of education, for

future individual patients 'will not come forward if doctors are going to squeal on them' 'X Health Authority v. Y [1988] R.P.C. 379.

³² See, for example, the recent case of *Z v. Finland* [1997] Application 22009/93.

³³ In *Z v. Finland*, above, the European Court of Human Rights held that Finnish legislation compelling Z's medical advisers to give evidence about Z's health status was not in breach of Article 8. This information was disclosed in the course of a prosecution against Z's ex-husband, who was charged with attempted manslaughter for deliberately subjecting others to risk of HIV infection and sexual assault. The European Court found that disclosure of Z's HIV status was not a breach of the right to respect for private life, since Z's privacy was legitimately abrogated in order to prevent crime and protect the rights and freedoms of others. The Court did rule, however, that the failure of the Finnish courts to keep Z's identity confidential did not justify the interference with her private life and on this ground, the complaint was upheld.

³⁴ In *Douglas v. Hello! Ltd* [2001] E.M.L.R. 9, the judges embraced the possibility of a 'right' to privacy with varying degrees of enthusiasm. Sedley L.J. offered the boldest endorsement of legally enforceable privacy right, stating that "... we have reached a point at which it can be said with confidence that the law recognises and will appropriately protect a right of personal privacy", p. 235. He later, however, declined to determine whether the common law had evolved to such an extent that a free standing privacy right could be identified to replace the "present, piecemeal protection of privacy", p. 239.

³⁵ See, for example, the articulation of privacy rights by Warren and Brandeis [18].

³⁶ *X and Y v. Netherlands* (1985) A 91, para. 22; *Gaskin v. UK* [1990] op. cit; *Niematz v. Germany* (1992) A 251-B, para. 29.

³⁷ Any allegation must be proved by the defendant to be 'true in substance and in fact': *Sutherland v. Stopes* [1925] AC 47.

³⁸ Note for example the Contempt of Court Act 1981, which makes it a criminal offence for a person to publish information to the public at large, or to a section of the public, which tends to interfere with the course of justice in particular legal proceedings (section 1). The Public Order Act 1986 makes it an offence to incite racial hatred. A person may be convicted of the offence in the publication of purportedly truthful statements (section 19) if those statements are likely to stir up racial hatred. That the defendant did not intend to stir up racial hatred or that the statements are true will not constitute a defence.

REFERENCES

1. The Human Genetics Commission. *Whose Hands on Your Genes?* London: The Human Genetics Commission, 2000 (<http://www.hgc.gov.uk/>).
2. Takala T. Gylling HA. Who should know about our genetic make-up and why? *Journal of Medical Ethics* 2000; 26: 171-174.
3. Dworkin R. Rights as trumps. In: Waldron J, ed. *Theories Of Rights*. Oxford: Oxford University Press, 1984: 153-167.
4. Harris J. *The Value of Life*. London: Routledge, 1985.
5. Osiel M. *Obeying Orders: Atrocity, Military Discipline and the Law of War*. London: Transaction, 1999.
6. Harris J. Euthanasia and the value of life. In: Keown J, ed. *Euthanasia Examined: Ethical Clinical and Legal Perspectives*. Cambridge: Cambridge University Press, 1995: 6-22.

7. Canellopoulou Bottis M. Comment on a view favouring ignorance of genetic information: confidentiality, autonomy, beneficence and the right not to know. *European Journal of Health Law* 2000; 7: 173–183.
8. Laurie G. Protecting and promoting privacy in an uncertain world: further defences of ignorance and the right not to know. *European Journal of Health Law* 2000; 7: 185–191.
9. Kennedy I. Grubb A. *Medical Law*. London: Butterworths, 2000.
10. Clarke A. Flinter F. The genetic testing of children: a clinical perspective. In: Marteau T. Richards M, eds *The Troubled Helix*. Cambridge: Cambridge University Press, 1996: 164–177.
11. Harris J. Genes, clones and human rights. In: Burley JC, ed. *The Genetic Revolution and Human Rights: The Amnesty Lectures 1998*. Oxford: Oxford University Press, 1999: 61–95.
12. Robertson J. *Children of Choice*. Princeton: Princeton University Press, 1994.
13. Harris J. Test is best. Lead Opinion article in *The Guardian* September 25th 1999.
14. Laurie G. In defence of ignorance: genetic information and the right not to know. *European Journal of Health Law* 1999; 6: 119–132.
15. Husted J. Autonomy and a right not to know. In: Chadwick R. Levitt M. Shickle D, eds *The Right to Know and the Right Not to Know*. Aldershot: Ashgate, 1997: 55–68.
16. Brazier M. Harris J. Public health and private lives. *Medical Law Review* 1996; 4: 171–192.
17. Ngwena C. Chadwick R. Genetic diagnostic information and the duty of confidentiality: ethics and law. *Medical Law International* 1993; 1: 73–75.
18. Warren S. Brandeis L. The right to privacy. *Harvard Law Review* 1890; 4: 193–220.

University of Manchester

School of Law

Williamson Building

Oxford Road

Manchester M13 9PL

UK

E-mail: john.harris@man.ac.uk

kirsty.keywood@man.ac.uk