4 Confidentiality

INTRODUCTION

It might at first be thought that the issue of medical confidentiality is straightforward. Health care professionals should always keep secret their patients' confidential information and it is as simple as that. As Lord Phillips MR in *Ashworth Security Hospital v MGN Ltd*[1] stated:

> It is well settled that there is an abiding obligation of confidentiality as between doctor and patient, and in my view when a patient enters a hospital for treatment, whether he be a model citizen or murderer, he is entitled to be confident that details about his condition and treatment remain between himself and those who treat him.

However, as we shall see the issue is complex. Modern health care systems would be unworkable if a doctor never passed on medical information about patients to other medical professionals. Also a moments thought will be able to conjure up situations where even information given in confidence to a doctor should be revealed. For example, if a father confesses to his doctor that he is abusing his child is the doctor to do nothing?[2]

Current medical practice has certainly made the issue of confidentiality more complex. A patient in a hospital is likely to be treated by a large number of health care professionals each dealing with different aspects of her treatment. Each one may need to have access to her medical records. Also internal and external audits of NHS Trusts may require managers to have access to at least parts of a patient's medical records to be able to ensure high standards of treatment are being offered. Further the inevitable increase in use of computer technology in relation to patients' records, while easing the passing of information to those who need to know, makes protecting confidentiality more complex.[3]

Despite these modern pressures on confidentiality the notion that a doctor should not improperly divulge sensitive information about his or her patient is deeply ingrained. The Hippocratic Oath states:

[1] [2000] 1 WLR 515, at 527.

[2] A doctor who did nothing after receiving a report of abuse in 1975 was found not to be negligent when assessed by the standards of doctors at that time *C v Dr A J Cairns* [2003] Lloyds Rep Med 90. The judgment assumes that things would be very different today.

[3] The NHS Plan (2000) promotes the use of electronic health records (now known as NHS Care Records). Electronic health records in the NHS are discussed in Cambridge Health Informatics Ltd (2001a).

> Whatsoever things I see or hear concerning the life of men, in my attendance on the sick or even apart therefrom, which ought not to be noised abroad, I will keep silence thereon, counting such things to be as sacred secrets[4].

The World Medical Association's International Code of Medical Ethics[5] declares:

> A doctor shall preserve absolute secrecy on all he knows about his patient because of the confidence entrusted to him.

Confidentiality is seen as an essential aspect of effective medical treatment. As the BMA has put it:

> Frank and open exchange between health professional and patients is the ideal and patients need to feel that their privacy will be respected before they can enter into such an exchange[6].

Indeed it is difficult to find anyone working in the medical field who believes that confidentiality is unimportant, even though there are certainly disputes over when confidentiality can properly be breached. However, as we will see later in this chapter, although the principle of confidentiality has received much praise, some believe it is honoured as much in the breach as in the observance. There have even been complaints that medical ethicists themselves in their writings have discussed individual patient's cases, thereby failing to pay sufficient attention to issues of confidentiality.[7]

One important point which is now being taken seriously in the NHS is that confidentiality is not just a negative concept: the obligation on staff not to reveal information. But it also contains a positive obligation: the NHS must take steps to ensure that confidential information is not revealed. This has led to some to shift the focus of the discussion away from confidentiality and instead on to the notion of data protection.[8] The emphasis reflects the view that the greater threat to medially sensitive information is not doctors selling our health records to the tabloid press, but hackers entering NHS computers and accessing private information. NHS authorities and trusts are required to appoint Caldicott Guardians[9] whose job it is to ensure the protection of confidential information within their organisation.

The General Medical Council has also issued strict guidelines in relation to confidentiality based on the following principles:[10]

> Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the

[4] Kennedy and Grubb (2001: 1047).
[5] Quoted in Beachamp and Childress (2001: 304).
[6] BMA (2004: 165).
[7] Rogers and Draper (2003).
[8] Montgomery (2003: 252).
[9] Named after the report which recommended them: Caldicott (1997).
[10] GMC (2004).

information they need in order to provide good care. If you are asked to provide information about patients you must:

- inform patients about the disclosure, or check that they have already received information about it;
- anonymize data where unidentifiable data will serve the purpose;
- be satisfied that patients' know about disclosures necessary to provide their care, or for local clinical audit of that care, that they can object to these disclosures but have not done so;
- seek patients' express consent to disclosure of information, where identifiable data is needed for any purpose other than the provision of care or for clinical audit—save in the exceptional circumstances described in this booklet;
- keep disclosures to the minimum necessary; and
- keep up to date with and observe the requirements of statute and common law, including data protection legislation.

The Department of Health has recently published guidelines on the issue of confidentiality within the NHS. But notice in this opening statement how the emphasis is more on fairness of dealing with information, rather than keeping it confidential:

> The NHS is committed to the delivery of a first class confidential service. This means ensuring that all patient information is processed fairly, lawfully and as transparently as possible so that the public:
>
> - understand the reasons for processing personal information;
> - give their consent for the disclosure and use of their personal information;
> - gain trust in the way the NHS handles information; and
> - understand their rights to access information held about them.[11]

These principles and the duties of confidentiality apply to all NHS staff, including volunteer helpers,[12] not just to doctors.

1 The legal basis of confidentiality

Perhaps surprisingly the legal basis of a medical professional's duty of confidentially is far from clear. There is not a single statute or common law body of laws governing confidentiality.[13] A medical professional who improperly discloses private information

[11] DoH (2003: 4).

[12] DoH (2003: 16).

[13] Law Commission (1981) recommended the creation of a new statutory tort of breach of confidence, but the proposal was never take up.

can be found to have acted illegally on the basis of a wide range of legal obligations, as follows:

1.1 Contract law

It might be said that to reveal a patient's confidential information is a breach of contract with the patient. However, there is no contract between an NHS patient and anyone caring for them. A court might find a special implied contract but the general view is that that is unlikely. A contract claim would, however, have a greater chance of success in a case involving a private patient.

A breach of contract claim could also arise if (as is likely) infringing patient confidentiality was a breach of the healthcare professional's contract of employment.[14] The claim and any remedy would, however, only be open to the employer, not the patient.[15]

1.2 Tort law

Revealing confidential information could amount to negligence. It is well established that keeping a patient's affairs private is part of reasonable care. A claim could be brought against a medical professional in tort if either the professional revealed the protected information, or failed to take reasonable steps to ensure that others did not get hold of it.[16] The difficulty in such a claim is, however, damages. Generally in tort damages are only available for financial or physical loss. Feelings of embarrassment, for example, would not be a recognized form of financial loss in tort law. Therefore, even if a successful claim could be brought in negligence only very limited damages might be available.

If the released information was untrue and led to reasonable people thinking less of the patient then a claim could be brought in defamation. However, this will only assist a patient if the information disclosed is false. Reassuringly for doctors they also have a defence of 'qualified privilege' if they reasonably believed their statement to be true and have communicated with a person a legitimate interest in the relevant information.[17] This would be relevant in a case where a doctor supplied information in a medical questionnaire for an insurance company which was reasonably believed to be correct, but which was, in fact, not.

Some have suggested that very soon the courts will recognize a new tort of breach of privacy. The argument has gained particular weight following the enactment of the Human Rights Act. The issue has recently been considered by the House of Lords in *Wainwright v Home Office*[18] who confirmed the orthodox position that in English tort law there is not a tort of infringing privacy. However, the case has not resolved all debate over the issue because their Lordships left to another day the question of whether the

[14] *X v Y* [1988] 2 All ER 649.

[15] Unless a patient could claim under the Contracts (Rights of Third Parties) Act 1999.

[16] *Swinney v Chief Constable of the Northumbria Police* [1996] 3 All ER 449.

[17] Brazier (2003: 70).

[18] [2003] 3 WLR 1337.

Human Rights Act could be relied upon to extend the existing tort law to ensure privacy was protected. Lord Nicholls in *Campbell v MGN*[19] referred to the tort of misusing private information. However, this tort was identical to the equitable obligation of confidence and their other lordships preferred to describe it in terms of an equitable obligation, rather than a tort.

1.3 Equitable obligations of confidence

Often the best claim for a patient who wishes to commence a legal claim in respect of a revelation of medical information is to rely on the equitable obligation to respect confidential information. In order for information to be protected by equitable obligations of confidence four criteria need to be satisfied:[20]

(i) The information must be of a personal, private or intimate nature.[21] The test for this is whether the person whom the information concerns had a reasonable expectation that the information would be kept private.[22] This will generally be true of medical information. This requirement indicates that if a doctor were to reveal a trivial piece of information (e.g. what colour socks a patient was wearing) this may be regarded as not protected by confidence. However, it should be noted that the BMA has suggested that even the fact a patient visited a doctor should be regarded as confidential information.[23] Lady Hale in *Campbell v MGN* surprisingly stated:

> Not every statement about a person's health will carry the badge of confidentiality or risk doing harm to that person's physical or moral integrity. The privacy interest in the fact that a public figure has a cold or a broken leg is unlikely to be strong enough to justify restricting the press's freedom to report it. What harm could it possibly do?[24]

This statement might be read as suggesting that minor medical complaints are not to be regarded as confidential. However it is better understood as a statement that with minor medical complaints it will not be particularly difficult to find public interest reasons (e.g. freedom of the press) that justify breaching the confidence.

(ii) The information must be imparted in circumstances imposing an obligation of confidence.[25] It used to be thought that there needed to be shown that there was a confidential relationship between the parties such as doctor-patient or husband-wife,

[19] Para 15.

[20] The leading book on breach of confidence is Gurry (1985).

[21] *Stephens v Avery* [1988] 2 All ER 477, *Campbell v MGN* [2004] UKHL 22.

[22] *Campbell v MGN* [2004] UKHL 22 (Lord Nicholls (para 21), Lady Hale (para 137)). Lord Hope preferred the test whether it would cause the victim 'substantial offence' (para 92); but this test was rejected by Lord Hoffman (at para 22) and Lady Hale (at para 135).

[23] BMA (2002: 167).

[24] *Campbell v MGN* [2004] UKHL 22, para 157.

[25] Lord Hoffman in *Wainwright v Home Office* [2003] 3 WLR 1337, para 29 stated that to establish a breach of confidence it was no longer necessary to show that the parties were in a confidential relationship.

but now it is clear that all that is required is that a person receives information which he knows or ought to know is fairly and reasonably to be regarded as confidential or private.[26] There is therefore little doubt that information provided to a doctor by a patient would satisfy this criterion. Indeed even words spoken in group therapy sessions have been said to be bound by confidence in this regard.[27] The duty of confidence will also apply to someone who is discovers information and it is clear that the person whom it concerns had a reasonable expectation that it would be kept private.[28] So if a doctor told his wife about a patient's medical condition she would also be bound by the duty of confidence because she would be aware that the information was confidential in its nature. Similarly if a member of the public found medical notes which had been accidentally left on a park bench the member of the public would be required to keep the information confidential.

(iii) It may be necessary to show that someone will suffer as a result of the release of confidential information about them. This was the basis of the reasoning in *R v Department of Health ex p Source Informatics Ltd*[29] which held that the release of anonymized medical information was not a breach of confidentiality. However it is not clear whether this represents the law because Lord Keith in *A-G v Guardian (No. 2)*[30] suggest that even if no one individual suffered a specific detriment in relation to the revelation, there could be a public interest that supported confidentiality. In other words even if the revelation did not itself harm a particular person if it could be said to have a public harm (e.g. to lead to a lack of trust in doctors) this could be sufficient to justify protecting the information in equity.[31] Hence it is widely accepted that even if a patient has died a doctor ought not to make public details of their medical conditions.

Confidence will be breached if only an unauthorized person sees it. It is not necessary to show that the information was made public.[32]

The leading case on breach of confidence is now *Campbell v MGN*. Their lordships emphasized that the right to respect for private and family life under article 8 of the European Convention on Human Rights should now be regarded as underpinning the protection of confidentiality. Protection of confidential information is about respecting the autonomy and dignity of individuals.[33] This meant that in deciding whether the information is protected by the law it would be necessary to consider whether the information is protected under article 8 and then whether infringement of the confidence is justified under paragraph 8.2.[34]

[26] *Campbell v MGN* [2004] UKHL 22, para 14 (Lord Nicholls), para 85 (Lord Hope).

[27] *Venables v MGN* [2001] 1 All ER 908.

[28] Lord Goff of Chieveley in *Attorney General v Guardian Newspapers Ltd (No 2)* [1990] 1 AC 109, 281.

[29] [2000] 1 All ER 786.

[30] [1988] 3 All ER 545.

[31] *Ashworth v MGN* [2001] 1 All ER 191.

[32] *A-G v Guardian (No 2)* [1990] 1 AC 109, 260.

[33] *Cambpell v MGN* [2004] UKHL 22, para 53 (Lord Hoffman).

[34] See e.g. Lord Nicholls, para 17.

KEY CASE Campbell v MGN [2004] UKHL 22

Naomi Campbell (and as Baroness Hale pointed out 'Even the judges know who Naomi Campbell is') was photographed leaving a meeting of Narcotics Anonymous. The Daily Mirror published the photographs accompanied by an article praising Ms Campbell's battle with drug addiction and giving details about her treatment. Naomi Campbell sued for breach of confidence. She won at first instance, lost in the Court of Appeal, but won again in the House of Lords. She was awarded £2,500 damages plus £1,000 aggravated damages.

The speeches in the House of Lords, unfortunately, are unclear on the basis of the award. Lord Nicholls talked of the tort of misuse of private information. However Lord Hoffman, Lord Hope and Baroness Hale all talked of equitable breach of confidence. Lord Hoffman also mentioned a new common law right to protect private information. Lord Carswell talked in general terms about a right to confidentiality but it is not clear what kind of right he was talking about. This lack of certainty is explicable because none of their Lordships suggested that the law differed depending on what classification was used. They were united in agreeing that the law would protect an improper revelation of confidential information be that through tort, equity or some unclassified right.

The first issue was whether details about Naomi Campbell's attendance at Narcotics Anonymous meetings were confidential. Lord Hoffman explained that the protection of confidential information was about 'the right to control the dissemination of information about one's private life and the right to the esteem and respect of other people'. Their lordships explained that in considering what information was confidential consideration would be given to article 8 of the ECHR and the right to respect for private life. In deciding whether information was confidential Lord Hope suggested: 'the broad test is whether disclosure of the information about the individual ("A") would give substantial offence to A, assuming that A was placed in similar circumstances and was a person of ordinary sensibilities.' However Lord Hoffman and Baroness Hale did not approve of this test. They preferred to ask whether a person would have a reasonable expectation that the information would be kept confidential.

Applying this test to the facts of the case their Lordships agreed that *prima facie* the fact that someone was receiving treatment for drug addiction would be confidential information. However, in this case Naomi Campbell had made various public statements to the effect that she (unlike many other models) did not take drugs. By so doing she had made her drug-taking a public matter and so no longer confidential. Alternatively her statements created sufficient public interest to justify the press correcting the misleading impression she had created. But, the majority of their Lordships then held that her statements did not mean that every aspect of her drug-taking and treatment was now public information. The time, place and form of drug therapy was still confidential. To the minority (Lords Nicholls and Hoffman) the article was essentially about Campbell's treatment for drug addiction and that was not private because she had chosen to make that issue a public one. The information about where and when she was attending treatment was 'unremarkable and consequential' (in Lord Nicholls's view). To the majority revealing the fact she was attending Narcotics Anonymous was analogous to informing the public of what medical treatment a celebrity was receiving, which was clearly protected information.

Having decided that the taking of photographs and publication of the story was in breach of confidence the next question was whether there was a public interest (including freedom of the press) which justified the infringement. Quite simply this involved a balancing exercise between the right to respect for private life under article 8 of the ECHR and right to freedom of expression under article 10:

> the right to privacy which lies at the heart of an action for breach of confidence has to be balanced against the right of the media to impart information to the public. And the right of the media to impart information to the public has to be balanced in its turn against the respect that must be given to private life.

In making this balancing exercise Baroness Hale for one did not have great sympathy for either side,: 'Put crudely, it is a prima donna celebrity against a celebrity-exploiting tabloid newspaper.' And this might explain why even though the majority sided with Campbell the level of damages was small. What seemed to have influenced the majority was that a recovering drug addict is in a vulnerable position, needing all the support she can get. The publication of information about her treatment was likely to distress her at what might be a particularly vulnerable time. There was little public interest in the story and therefore the right to privacy trumped the right to freedom of expression.

The main disadvantage in relying on the equitable remedy is in relation to the remedies a court can grant. The primary remedy is an injunction. A court may be willing to prevent a disclosure of confidential information through an injunction if that is necessary in the public interest.[35] However, this is, of course, only useful to someone who is aware that there is about to be a revelation of confidential information and provides little assistance in a case where the revelation has already been made. It used to be thought that damages were not available. However, the Court of Appeal in *Cornelius v de Taranto*[36] upheld an award of damages for breach of confidence and, of course, the House of Lords in *Campbell* did. In neither case were the sums awarded very large. If the person breaching confidence thereby acquires a profit it may be he or she can be made liable to account for those profits to the victim.[37]

1.4 **Ownership**

It could be argued that a patient owns his or her medical information and therefore can bring a property claim if the information is revealed to others. But in *R v Department of Health, Ex Parte Source Informatics Ltd*[38] the Court of Appeal rejected an argument that a patient owns the information about themselves. Indeed, the general view seems to be that it is the NHS Trust which owns the records its staff makes.[39] The Trust (rather than

[35] *W v Egdell* [1990] 1 All ER 855.

[36] [2001] 68 BMLR 62.

[37] *Blake v Attorney-General* [2003] 1 WLR 625 and see the discussion in Feldman (2002: 619).

[38] *R v Department of Health ex p Source Informatics Ltd* [2000] 1 All ER 786.

[39] *R v Department of Health ex p Source Informatics Ltd* [2000] 1 All ER 786.

the staff) therefore can control the access to that information. That said in *R v Mid-Glamorgan FHSA ex p Martin*[40] it was emphasized that simply because someone owns records does not mean that they have the right to do what they want with them.

1.5 Criminal law

It has long been held that information is not property which is capable of being stolen.[41] However, the paper on which a medical report is contained could be. So, a doctor who handed over a piece of paper with a medical record or an X-ray to journalist could be guilty of theft, not of the information, but of the piece of paper on which it was written. If the doctor telephoned a journalist and read out a medical record there could be no theft conviction. The Computer Misuse Act 1990 also criminalizes 'hacking' into a database to access confidential information. Notably an offence under that Act is committed by staff who have access to some parts of a database but who access parts to which they are not authorized.[42] This means that a health professional is guilty of an offence under the Act if he accesses his hospital's database to discover information about a celebrity who is not his patient.

1.6 Human Rights

The Human Rights Act, as discussed in chapter 1, affects the law in two ways. It can be used to direct the interpretation of statute or develop the common law. Plus it provides a cause of action in its own right.

1.6.1 *Interpretation of statutes and common law*

Article 8 of the European Convention on Human Rights which protects the right to respect for private and family life also protects confidential information.[43] As the European Court of Human Rights in *Z v Finland*[44] explained:

> The protection of personal data, not least medical data, is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life as guaranteed by article 8 of the Convention . . . Without such protection, those in need of medical assistance may be deterred from revealing such information of a personal and intimate nature as may be necessary in order to receive appropriate treatment and, even, from seeking such assistance thereby endangering their own health and, in the case of transmissible diseases, that of the community.

It is now arguable that when the courts are interpreting statute or the common law they should as far as possible do so in a way which is compatible with the protection of

[40] [1995] 1 All ER 356.

[41] *Oxford v Moss* (1978) 68 Cr App R 183.

[42] *R v Bow Street Metropolitan Stipendiary Magistrate ex p Government of the USA* [2000] 2 AC 216.

[43] Phillipson (2003).

[44] (1998) 25 EHRR 371, para 95–6.

confidential information as required under article 8. Indeed we have seen in *Campbell v MGN* that the House of Lords relied on the European Convention on Human Rights in determining the extent of the confidentiality and in balancing the right to privacy and the right to freedom of expression. It should not be forgotten that it is permissible to infringe the right to respect for private life if one of the interests listed in article 8(2) are threatened. This will mean that it will only be permissible to disclose confidential information if to do so is 'necessary in a democratic society' in the interests of 'national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health and morals, or for the protection of the rights and freedoms of others.' This offers a stronger protection for individual rights of privacy than might at first be apparent. First, the word 'necessary' means not just reasonable or convenient, but that there is some pressing social requirement. Second, the European Court of Human Rights has interpreted the provision to emphasize the notion of proportionality. This means that the extent to which the confidence is interfered with must be the minimum required to protect the countervailing interest. In other words even if the interests of the protection of public health may justify interfering with the confidentiality of part of someone's medical records, it may not justify revealing them all.

In *Z v Finland*[45] a husband was being prosecuted for a crime. The prosecuting authorities needed to establish when he was aware of his HIV+ status. The police relied upon his wife's medical records for this purpose. The wife objected to the European Court claiming her article rights had failed. A number of important points come out of the decision. First, the Court indicated that some kinds of medical information were more sensitive than others and information about HIV status was particularly sensitive. The implication is that the more intimate the information, the stronger the countervailing interests had to be to justify receiving it. Second, the court held that accessing her medical records was justified in the name of pursuing criminal proceedings for a serious offence, but that that did not justify making her medical records public. It should have been possible for the evidence to have been made available in the trial without her right to respect for her private life being invaded. In other words the extent of the invasion of her confidence was disproportionate.

In *MS v Sweden*[46] the applicant applied for compensation for an industrial injury from social insurance benefits. The Social Insurance Office were sent information in her health records, including an abortion she had had as a result of the injuries. It was held this did not infringe her article 8 rights. The infringement with her rights of privacy were justifiably infringed in the name of checking the accuracy of the data. The officer checking the information was required to maintain the confidentiality of the information. One point that was emphasized seemed to be given attention by the Court was that she had chosen to apply for the benefit and had therefore raised publicly the state of health.

[45] (1997) 5 BMLR 107.

[46] (1998) 45 BMLR 1.

1.6.2 *Remedies under the Human Rights Act*

Section 7 of the Human Rights Act allows someone to sue a public authority which has infringed their convention rights. Section 8 permits the court to award damages on such an application. This would clearly enable a person whose records have been improperly revealed to others by the NHS to bring an application against the NHS under the Human Rights Act.

1.7 Statutory obligations

There are a number of statutes which impose particular obligations in relation to confidential information. The Data Protection Act is the most significant, although there are a host of other statutory instruments and provisions which impose duties of confidentiality in particular circumstances.[47] For example, a medical professional cannot disclose information about a patients' attendance at a fertility clinic[48] or genitourinary medicine clinic,[49] even to the patient's GP, without the express consent of the patient.

1.8 Professional disciplinary procedures

As well as the law a variety of professional bodies have issued guidelines on confidentiality. These include the BMA,[50] GMC[51] and the Nursing and Midwifery Council.[52] The NHS has also issued its own code on confidentiality.[53] These guidelines are clearer and more accessible to health care professionals than the law. No doubt most professionals simply ensure that they are following the relevant professional guidelines, rather than attempting to understand the legal position. They make the assumption that if they are following the guidelines they are acting lawfully. This is probably a reasonable assumption to make. Notably the courts have on occasion relied upon the professional guidelines when deciding what the legal position was.[54] This is understandable if the basis of confidentiality is the tort of negligence which places much weight on the accepted professional standards. If the law is based on human rights or equitable obligation of confidence it is arguable that it is wrong to assume that following professional guidelines will necessarily provide a defence to any legal action. That said it is difficult to imagine that a judge would ever penalize a professional who had followed her professional guidelines. So, although not technically law, these guidelines are likely to play a

[47] E.g. NHS (Venereal Diseases) Regulations 1974, SI 1974/29; NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000.

[48] Human Fertilisation and Embryology Act 1990, as amended by the Human Fertilisation Embryology (Disclosure of Information) Act 1992.

[49] National Health Service (Venereal Diseases) Regulations 1974, SI 1974/29.

[50] BMA (2004).

[51] GMC (2004).

[52] Nursing and Midwifery Council (2002).

[53] DoH (2003).

[54] *Re C* [1996] 1 FCR 605, *W v Edgell* [1990] 1 All ER 835.

significant role in the interpretation of the law on confidential information in this context. We will now introduce four of the most important guidelines.

1.8.1 *The Nursing and Midwifery Council*

The Nursing and Midwifery Council provides guidance on confidentiality in their *Code of Professional Conduct*.[55] It emphasizes that 'You must treat information about patients and clients as confidential and use it only for the purposes for which it was given.'[56] It states that disclosure of patients' information should not take place without their consent, with two exceptions:

- they can be justified in the public interest (usually where disclosure is essential to protect the patient or client or someone else from the risk of significant harm),
- they are required by law or by order of a court.[57]

1.8.2 *The General Medical Council*

The Guidelines issues by the GMC also emphasize the importance of ensuring that confidences are respected.[58] It regards the consent of the patient as the primary exception to the principle that confidential information must be kept secret. However, it also accepts that where secrecy would risk death or serious harm to the patient or another person disclosure is permitted. The GMC guidance emphasizes that patients should be told at the outset how information about them is to be used. If a patient refuses to permit the sharing of their records with others caring for them this must be respected.

The GMC suggests that a disclosure of confidential information is only exceptionally justifiable:

> Personal information may be disclosed in the public interest, without the patient's consent, and in exceptional cases where patients have withheld consent, where the benefits to an individual or to society of the disclosure outweigh the public and the patient's interest in keeping the information confidential. In all cases where you consider disclosing information without consent from the patient, you must weigh the possible harm (both to the patient, and the overall trust between doctors and patients) against the benefits which are likely to arise from the release of information.[59]

1.8.3 *NHS guidelines*

The Department of Health has issued a code of practice designed to ensure the protection of confidential information. At the heart of the guidance is the following principle:

> Patients entrust us with, or allow us to gather, sensitive information relating to their health and other matters as part of their seeking treatment. They do so in confidence and

[55] Nursing and Midwifery Council (2002).

[56] Para 5.1.

[57] Para 5.3.

[58] GMC (2004).

[59] GMC (2004: 22).

> they have the legitimate expectation that staff will respect their privacy and act appropriately. In some circumstances patients may lack the competence to extend this trust, or may be unconscious, but this does not diminish the duty of confidence. It is essential, if the legal requirements are to be met and the trust of patients is to be retained, that the NHS provides, and is seen to provide, a confidential service. What this entails is described in more detail in subsequent sections of this document, but a key guiding principle is that a patient's health records are made by the health service to support that patient's healthcare.[60]

The Code makes it clear make that duties of confidentiality apply not just doctors but also:

- all NHS bodies and those carrying out functions on behalf of the NHS have a common law duty of confidence to patients and a duty to support professional ethical standards of confidentiality;
- everyone working for or with the NHS who records, handles, stores or otherwise comes across information has a personal common law duty of confidence to patients and to his or her employer. This applies equally to those, such as students or trainees, on temporary placements;
- health professionals have, by virtue of professional regulation, an ethical duty of confidence which, when considering whether information should be passed on, includes paying special regard to the health needs of the patient and to his or her wishes;
- other individuals and agencies to whom information is passed legitimately may use it only as authorized for specific purposes and possibly subject to particular conditions.[61]

1.8.4 *The British Medical Association*

The BMA sees the importance of confidentiality from a broad perspective. Its guidance on confidentiality opens with the following statement:

> Respect for privacy allows people time and space to express their thoughts and feelings without fear of being misunderstood or judged by unsympathetic third parties. It has been described as being essential for 'sexual, religious, and imaginative impulses to flourish' as well as necessary for people making important life choices such as those related to medical treatment. Despite this, people are often interested in the private lives of others. In medicine, others—typically relatives or employer—sometimes believe that it is important for the protection of their own interests to discover information about patients. Health professionals' duties of confidentiality prevent such access without patients' consent.[62]

However, the guidance goes on to emphasize that confidentiality is not an absolute right and can be breached in order to protect the rights of others or the public interest.[63]

[60] DoH (2003: 7).
[61] DoH (2003: 4.1).
[62] BMA (2004: 165).
[63] BMA (2004: 166).

1.9 Comments on the law

It must be admitted that the law in this area is not very satisfactory. There have been few cases governing the issue and there appear to be large number of branches of the law that govern the area. A number of points can however be made to reassure the reader. The first is that as already indicated, professional bodies have provided fairly clear guidance on the obligations of confidentiality and the courts are likely, in areas of doubt, to ensure that the law coincides with professional guidance. Second, the courts have indicated that when considering the legal position of confidence whether the obligation is seen as emanating from contract, tort, or equity the extent of the obligation will be the same.[64] Third, the paucity of the case law may indicate that this is not an area where clear legal regulation is required, professional responsibilities appear to adequately protect patient's confidentiality. Although it might be that lack of clarity discourages people from bringing legal proceedings.

REALITY CHECK

Confidentiality In Practice

As we have seen in theory the law takes breaches of confidentiality seriously, but in real life how well is confidentiality protected?

According to David Stone, 'many observers would say that, at ground level, the rights and duties arising from patient confidentiality are honoured more in the breach than the observance' (Stone (2001 :132)). As he points out such a large number of people will have access to the records and they cannot realistically be described as private. One writer explains that at least 25 and possibly 100 health care professionals and administrative personnel at one university hospital deal with a particular patient's records (Gillon (1986: 109)). But this kind of use of information is probably not objected to by many people.

The kind of case which is more likely to give concerns to members of the public is the following mundane case:

> Over a golf match between a dentist and a GP the two men discovered they shared a patient. The GP told the dentist that the patient had had an abortion. The dentist told his wife, who told a friend. The friend mentioned it to the patient. (mentioned by BMA (2002: 167))

It is this kind of revelation of personal information to a person's social circle which is the main concern of many patient (Siegler (1982), Shakar et al (2003)). Another kind of incident which raises ire in the media is the finding of confidential medical reports in public waste bins or on the street (see e.g. BBC Newsonline (2003b)).

Interestingly people in one survey were not particularly concerned about doctors seeing their medical records, but were unhappy about receptionists receiving it (NHS Information Authority (2002: 6)).

[64] Montgomery (2003: 262).

An Observer investigation (Browne (2000)) discovered some concerning breaches of confidentiality including:

- A 68-year-old man was refused a place in a care home when social services found from his medical records that he was gay.
- An uncle found out that his niece had a secret abortion when the company he worked for was asked to do a financial audit of the local health authority. He told her parents, who were very religious.
- A woman was sacked after her GP sent her records to her employer. The notes revealed that she had a history of mental health problems.
- An MP was sent the medical records of a constituent without her consent. She found out only when the MP passed on the records to her.

A survey by the Audit Commission in 1995 revealed rather lax attitudes when it looked at hospital records. The report stated 'In nearly two thirds of the hospitals visited case notes were taken out of the hospital by clinical staff for research and other purposes. They had been known to be left under the doormat in doctors' residences and in the boots of cars. In one instance a doctor sold his car with patients' case notes still in the boot.' (Audit Commission (1995: 31)). It may be that since the report attitudes within the NHS towards confidentiality have changed. As already mentioned there has in recent years in moving away from seeing confidentiality as a negative concept ('don't reveal private information') to data protection as a positive concept ('make sure that private information does not become public'). The NHS has talked about the need to create a 'Confidentiality culture' (NHS Information Authority (2002: 6)). However there is at least anecdotal evidence that doctors are often overheard discussing patients personal medical details on trains (Hendricks (2003)) in parties (Weiss (1982)) and lifts (Vigod, Bell and Bohnen, (2003)). Interestingly the NHS code on confidentiality has seen it necessary to spell out the requirement not to discuss patient's confidential information in public places (DoH (2003)). Another concern in a study is the willingness of GP surgeries to reveal personal information about patients to telephone callers, without checking their identity (Russell (2003): 25 out of 46 surgeries gave out contact details of patients without checking the identity of the caller).

Interestingly from the perspective of the NHS workers one of the main challenges in relation to medical records is not the problem in keeping the records private but the burden of complying with requests for medical records from solicitors or others pursuing personal injury claims of people's behalf (Research Works Ltd (2004)).

One final point in hospital many consultations on the ward take place with only the flimsiest of curtains between patients. These may offer the pretence of privacy, but it is difficult to believe that they ensure that conversations are not overheard.

2 Defences to alleged breach of confidentiality?

It is arguable that the easiest way to look at the law is to consider what defences someone might raise to a claim that they wrongfully revealed confidential information and that is how we shall proceed.

2.1 The information is not confidential

It may be argued that the information lacks any element of confidentiality. Really this is not a defence as a breach of confidence claim, but rather an argument that the information is not protected by the law on breach of confidence. In the House of Lords decision in *Campbell* it was held that information is confidential if someone had a reasonable expectation that it would be kept confidential. It is generally thought that information can acquire its confidentiality from two sources:

(i) The information is given in the context of a relationship which is of a kind is based on an assumption of confidentiality. There is little doubt that doctor-patient relationship is of this kind.

(ii) The information is itself of a private and intimate kind and therefore must be kept confidential.

It should be noted that information can be regarded as confidential if it falls in either of these categories.

There are two main issues of dispute. What if information given to a health care professional by a patient is trivial. For example, if a law professor tells his doctor that he loves the television programme *Big Brother* and the doctor tells her friend, this could be regarded as a breach of confidence, even though love of *Big Brother* is not a particularly intimate piece of information? Is the fact that the doctor acquired the information as a result of the confidential relationship between them enough to render the information confidential?[65] In *R (Stevens) v Plymouth*[66] it was suggested that 'straightforward descriptions of everyday life' of a patient would not be regarded as confidential. On the other hand in *Ashworth Hospital Authority v MGN Ltd*[67] an argument that information about a patient was too trivial to be protected by confidentiality was rejected on the basis that confidentiality contained a subjective element. In other words that a person would be entitled to regard a piece of medical information about themselves as sensitive, even if most people would not regard it as particularly private. Of course if the information revealed is not particularly damaging, there is unlikely to be a legal remedy of any significance, even if technically there is a breach of confidence. The professional guidance is not in agreement. The GMC guidelines states that 'patients have a right to expect that

[65] BMA (2002: 167) suggests that even if the information is not 'medical' it can still be regarded as confidential.

[66] [2002] 1 WLR 2483.

[67] [2001] 2 All ER 991.

information about them will be held in confidence by their doctors.'[68] This appears to relate to all information a patient gives a doctor. The BMA guidelines states that 'all information collected in the context of health care' is covered.[69] The NHS code states: 'A duty of confidence arises where one person discloses information to another . . . in circumstances where it is reasonable to expect that the information will be held in confidence'.[70] This might be read as suggesting trivial or non-intimate information can be revealed.

Second, what if a doctor is given information when he or she is not acting in his or her professional capacity? It is generally thought that if a doctor is given private information as a doctor it must be kept confidential.[71] For example, if a person at a party takes a doctor aside and asks for some medical advice then what the person says should be kept confidential. But if the doctor is given information, not as a doctor, but as a piece of gossip between friends, (for example, she is told a neighbour is having an affair) this will not necessarily attract confidentiality, but may do so if it is the kind of information which a reasonable person would expect to be kept confidential.[72] Some commentators argue that if the neighbour or the person telling the doctor was a patient of hers that would change the issue and the information would then become confidential.

2.2 The information is no longer confidential

Even if it is accepted that the information was confidential, it might be argued that the information has lost its confidential nature. Confidentiality can be lost if the information has become public. If, therefore, a patient has revealed his medical condition to the press, there can be no complaint if the doctor subsequently reveals that same information.[73] Remember in *MGN v Campbell*[74] by making public statements that she did not take drugs it was suggested that Naomi Campbell had made some information about her drug taking non-confidential. As that case shows, however, just because some knowledge about a medical condition has been made public does not mean that others are free to reveal everything relating to the condition and its treatment.

2.3 The disclosure does not breach the confidentiality

Even though it is admitted that there has been a disclosure of confidential information it might be argued that the disclosure was not in breach of the obligation not to disclose. There are two main situations in which such a claim could be made:

[68] GMC (2004: 1).
[69] BMA (2004: 167).
[70] DoH (2003: 7).
[71] Kennedy and Grubb (2001: 1062).
[72] BMA (2002: 167) leaves the question open.
[73] See also *Douglas v Hello!* [2001] 1 WLR 992.
[74] [2004] UKHL 22.

(i) Consent. Fairly obviously if the patient is happy for information to be disclosed, then there is no breach of confidence. A husband may, for example, ask a doctor to discuss his medical condition with his wife. The GMC in its guidance states:

> When seeking express consent to disclosure you must make sure that patients are given enough information on which to base their decision, the reasons for the disclosure and the likely consequences of the disclosure. You should also explain how much information will be disclosed and to whom it will be given.[75]

(ii) In a highly controversial decision it was held that the release of confidential information in an anonymized form was not in breach of a duty of confidentially. It is worth considering the decision in further detail:

KEY CASE R v Department of Health, Ex Parte Source Informatics Ltd [2001] QB 424 (CA)

Source Informatics Ltd were in the business of selling medical information to pharmaceutical companies. They started a scheme under which GPs and Pharmacists would pass to them information about drugs prescribed for patients. This information included the doctor's name, and the amount and name of drug prescribed. The name of the patient was removed from any information passed on. The GPs and Pharmacists were given a small sum of money for doing this. The Department of Health issued guidelines that the passing on this information (even with the patient's name removed) breached the professional's confidentiality to patients. Source Informatics Ltd sought a judicial ruling on the Department of Health's guidelines. The Court of Appeal held that even though the patients had not consented to the passing on their medical information because the information was anonymized there was no breach of confidentiality. Nor could the patient claim any property in the prescription forms from which the information was taken or the information itself.

The key passage in the judgment is as follows:

> the confidant is placed under a duty of good faith to the confider and the touchstone by which to judge the scope of his duty and whether or not it has been fulfilled or breached is his own conscience, no more and no less. One asks, therefore, on the facts of this case: would a reasonable pharmacist's conscience be troubled by the proposed use to be made of patients' prescriptions? Would he think that by entering Source's scheme he was breaking his customers' confidence, making unconscientious use of the information they provide? (Simon Brown LJ, at para 31).

The answer to the questions in the Court of Appeal's view was clearly no. There was no identifying information and therefore the patient's privacy was not infringed and therefore the doctors and pharmacists were not acting in breach of their duty of good faith.

[75] GMC (2004: para 16).

The decision in *R v Department of Health, Ex Parte Source Informatics Ltd*[76] is highly controversial. It is important to separate out two questions here. The first is whether the disclosure of anonymized medical information is in breach of confidence. The second is whether the disclosure is justified if necessary in the public interest for the purposes of medical research. The controversy surrounds the former decision. The Court of Appeal's approach is that because no one can know whose medical details are being looked at there can be no harm, no invasion of privacy and therefore no wrong is committed.[77] However that is debatable. If a nude photograph of a person was published in a newspaper without their consent, with their face obscured so they could not be identified that person may well feel wronged, even though no one would know it was them. Their private and intimate space had been invaded, even if no one else but them realised it. Could not the same thing be said about someone's private medical details? The decision has also been criticized on the basis that it appears to suggest that a breach of confidence is only a wrong if there is unfairness or loss to someone, rather than seeing the breach of confidential information being a *prima facie* wrong for which a justification must be produced.[78]

The Court of Appeal's assumption was that the general public would not object to their medical information being used if it was anonymized. That assumption is contestable. In fact the research shows a mixed picture with some surveys suggesting the general public have no such objection and others that they do.[79] The decision also provides no option for a person who objects to their information being used for the basis of particular kinds of research. A patient may have strong moral objections to research in relation to contraception or which involves animals, and yet have no power to object to their medical information for use in such research.[80] A person's information may also be used in a way which (indirectly) harms them. Their anonymized information might, for example, show that people of a particular ethnic or cultural group were more susceptible to a certain disease and such a finding could have negative impacts for all members of that group, for example making it difficult for them to obtain mortgages.[81]

Data which contains the postcode (but not the name) of the patient is regarded by some people as anonymous.[82] The postcode is useful if research is being carried out in an attempt to ascertain whether certain conditions are more prevalent in particular parts of the country. However some argued that it can be all too easy to discover the identity

[76] *R v Department of Health ex p Source Informatics Ltd* [2000] 1 All ER 786.

[77] O'Neill (2003) and Warnock (1998).

[78] Mason McCall Smith Laurie (2001: 258). For criticism of its interpretation of the Data Protection Act see Beyleveld and Histed (2000).

[79] Research by Wilison, Kashavjee, Nair, Goldsmith, Holbrook (2003) found that patients drew no distinction between identifiable and anonymous data. But NHS Information Authority (2002) found patients happy not to be asked for consent if the information was anonymized. Morgan (2001) found 61% of his sample did not want their medical details used for research even if it was anonymized.

[80] Chester (2003).

[81] Gostin (1995: 521).

[82] GMC (2004) suggests that to be anonymized information it must not contain a full postcode.

of a person given their postcode a few pieces of health information.[83] Critics reply that it is fanciful that someone will seek to discover the identity of individuals from amongst a mass of research data.

The most fundamental aspect of the decision in *Source Informatics* is its shift in focus from protection of confidential information to fairness of use. As long as the user can show they were acting in good faith with personal information they are not acting in breach of confidence. This shift from protecting the privacy of the patient, to focussing on the conscience of the user could be highly significant.[84] The decision could even be read as shifting the burden from the user to show they had justifiable reasons for using the confidential information to the patient being required to show the use was in bad faith. The potential impact of the decision is therefore enormous. However the traditional approach that people have a right to have their private information protected underpins the professional guidance that has been issued and the Data Protection Act must still be followed.[85] Also the emphasis Lord Hoffman in *Campbell v MGN*[86] placed on right to privacy and autonomy as underlying the law on protection of confidential information suggests a very different approach from that promoted by *Source Informatics*.

Those keen to emphasize the importance of confidentiality can try and take a more positive spin on the decision in *Source Informatics*. The Department of Health Guidelines states that if information is disclosed it should be anonymized if possible.[87] A person wishing to reveal personal medical information must now first show that there are sufficient reasons for making the disclosure and secondly show why the disclosure cannot be made with the information first anonymized. This is most significant in the area of the use of medical information in research where it might be thought that only exceptionally would anonymous information not be sufficient for the task at hand. However, there can be difficulties in using anonymous data for research purposes, because it can be harder to ensure there are no duplicates.[88]

2.4 **Consent**

As already indicated there is no breach of confidence if the patient has consented to the release of the information. In fact it is rare for patients to be asked explicitly whether they consent to others seeing their information. This is because often medical professionals rely on implied consent.[89] When patients agree to be referred to a consultant by a GP, although they do not in so many words consent to the disclosure to the consultant of their medical history, they do by implication.[90] As we shall see this 'implied consent' can

[83] Chester (2003).

[84] See the discussion in Laurie (2002: 224).

[85] Laurie (2002: 228).

[86] [2004] UKHL 22, para 51.

[87] DoH (2004: 4.5).

[88] Chalmers and Muir (2003).

[89] BMA (2004: 177).

[90] But, a consultant should not pass on a report to a GP against the wishes of a patient: *Birmingham CC v O* [1983] 1 All ER 497.

be taken to authorize the use of information to a wide range of medical personnel.[91] So more generally, patients who give information to their doctors are presumed to consent to the information being provided to others in the health care system in the course of normal medical practice.[92] However, the current GMC guidance clearly states that express consent should be obtained for the sharing of information amongst a health team:

> Most people understand and accept that information must be shared within the health care team in order to provide their care. You should make sure that patients are aware that personal information about them will be shared within the health care team, unless they object, and of the reasons for this.[93]

Although this might be best practice it is likely that a court would accept that a patient impliedly consents to their information being shared amongst a health team if they had voiced no objection to this. The difficulty with using the implied consent model to such a wide range of medical professionals is that it assumes that a patient is aware that the information will be shared.[94] Although this is plausible in relation to a sharing of information between the doctors who are actually dealing with the patient the justification has been said by the Department of Health to cover also sharing information in the context of *inter alia*, clinical audit, investigating complaints,[95] monitoring public health and research.[96] Is it not a fiction to say the patient 'consents' to such use of information? This is especially so in circumstances where the revealing of information is not directly related to their treatment, but includes managers looking at the general running of the hospital.[97] Also, if implied consent is the basis of the law here does that mean that patients who state that they do not want their records to be viewed by anyone except the medical staff attending them must have those wishes respected?

Such concerns about an implied consent model could lead us in two directions:

(i) We should continue to accept that consent is the basis of the justification but we need to make sure patients are aware how widely their information will be distributed within the NHS and give them an opportunity to object to some of the uses.[98] If they do object then their wishes must be respected. The GMC has accepted this approach. Its guidance in relation to clinical audits explains:

[91] BMA (2004: 180).

[92] Information Commissioner (2002).

[93] GMC (2004: para 10).

[94] The Royal College of General Practitioners (2000: 1) is concerned about the reliance on implied consent.

[95] A GP about whom there has been a complaint by a patient can look only at the parts of the patient's medical records that relate to the complaint: DHSS (1988).

[96] DoH (1996).

[97] See the discussion in Cambridge Health Care Informatics Ltd (2001b).

[98] Some steps in this regard are mentioned in DoH (1996). See also GMC (2004: para 1) and British Psychological Society (2002).

> 13. . . . Where an audit is to be undertaken by the team which provided care, or those working to support them, such as clinical audit staff, you may disclose identifiable information, provided you are satisfied that patients:
>
> - have been informed that their data may be disclosed for clinical audit, and their right to object to the disclosure; and
> - have not objected.
>
> 14. If a patient does object you should explain why information is needed and how this may benefit their care. If it is not possible to provide safe care without disclosing information for audit, you should explain this to the patient and the options open to them.

Similar guidance is issued in relation to research.[99]

(ii) The alternative approach (which we will consider below) would be to abandon the implied consent model as too artificial and instead suggest that revelation to workers in the health care system should be seen as justified in the public interest.

2.5 'The proper working of the hospital'

As we have seen in a modern hospital medical information about patients is shared among a bewildering number of people. Accountability, monitoring and research may require confidential information to be processed by many within a hospital.[100] The breach of confidentiality could be justified on the basis that it is an essential part of the working of a modern national health care system.[101] As such it is justifiable in the public interest that a patient's medical information be available to any worker in the NHS who has a legitimate interest in viewing it. If such a justification were supported then arguably even if a patient objected public policy would justify the disclosure. In terms of article 8 it could be said that the breach of the patients' rights under article 8(1) is justified as necessary in the interests of the state under article 8(2).

There is little explicit legal support for this approach. In *R v Department of Health, ex p Source Informatics Ltd*[102] Simon Brown LJ suggested that using confidential information for legitimate NHS purposes was legitimate, even if done against a patient's wishes. However, he left open the question of whether this was because there was no breach of confidence, or because there was a public interest justifying the breach. There are also cases in banking law which have accepted an argument that confidential information can be used within a bank if necessary to enable the proper workings of the bank.[103]

[99] DoH (2003: para 12).

[100] DoH (1996: para 1.2). Even the Commission for Health Care Audit and Inspection has the power to look at unanonymized data (Dyer (2003)).

[101] BMA (2004: 180).

[102] [2000] 1 All ER 786.

[103] *Tournier v National Provincial and Union Bank of England* [1924] 1 KB 461.

2.6 A threat of serious harm to others

Threats of serious harm to others can justify revealing confidential information. There have been few cases dealing with this justification and so it is difficult to state the law with certainty. The most obvious explanation for this exception is that there is a public interest in protecting innocent people from harm and that this outweighs the public interest in protecting confidences. An alternative could be based on the principle that those who seek the protection of Equity must have clean hands. If a patient poses a risk to others he or she thereby forfeits the protection of the law on confidence. However, the equitable principle is founded on the notion of conscience and thus cannot explain why a patient who, through no fault of his own, poses a risk to others should lose the protection of the law. So the obvious explanation is the most popular one: given the choice between respecting confidentiality or protecting someone from death or serious harm a medical professional should choose the latter. It is not surprising that this exception is not controversial either among most ethicists,[104] practitioners nor members of the public.[105]

What is, however, a matter of some debate is how serious the harm to others must be before a breach of confidentiality is justified. The GMC advice is that there must be a serious risk of death or serious harm.[106] The British Psychological Society's guidelines for psychologists requires only a 'risk of harm'.[107] The Department of Health guidelines suggest:

> Murder, manslaughter, rape, treason, kidnapping, child abuse or other cases where individuals have suffered serious harm may all warrant breaching confidentiality. Serious harm to the security of the state or to public order and crimes that involve substantial financial gain or loss will also generally fall within this category. In contrast, theft, fraud, or damage to property where loss or damage is less substantial would generally not warrant breach of confidence.

The BMA guidance suggests that a risk of assault or a road traffic accident are sufficient to justify disclosure of confidential information, but not just a financial loss.[108] However, it went on to point out that this division between a threat of harm to person and property is not that straightforward. Serious fraud of the NHS delays treatment for patients and can thereby be said to cause physical harm.

The problem, as the BMA has pointed out, is that it is difficult for a medical professional to know whether the risk to others would be judged sufficiently serious to justify an interference until the courts rule on the issue. This can leave the professional in an 'invidious position'.[109]

The leading case on this exception is *W v Egdell*:[110]

[104] Morgan (2001: 166) thinks it will be very rare that the threat will be of sufficiently serious harm.

[105] Jones (2003).

[106] GMC (2004: para 22). BMA (2000: 190) suggest that serious harm can include psychological harm.

[107] British Psychological Society (2002: 4).

[108] BMA (2004: 190).

[109] BMA (2004: 190).

[110] [1990] 1 All ER 835.

KEY CASE W v Edgell [1990] 1 All ER 835

W had been convicted of manslaughter in connection with some extremely violent killings of five people. He was being detained in a secure hospital under the Mental Health Act 1983. Dr Edgell was asked to prepare a report for a mental health review tribunal which was considering whether W should be released. The doctor's report indicated that W was extremely dangerous. He went on to say that those caring for him did not appear to appreciate his dangerousness, particularly his interest in high explosives. When W's solicitors saw the report they decided to drop their application to the tribunal. Dr Egdell wanted to send a copy of his report to the Home Office and the medical director of the hospital caring for W. W applied to stop him disclosing the report. The Court of Appeal held that the disclosure of the report to those parties was justified. The Home Office and the hospital staff were not aware of W's dangerousness and the public interest justified the disclosure. It was legitimate to breach confidence where there was a real risk of significant harm to others.

Importantly Bingham LJ emphasized that the court was not saying that W's confidentiality was not protected at all '[Dr Edgell] could not lawfully sell the contents of his report to a newspaper . . . Nor could he without a breach of the law as well as professional etiquette, discuss the case in a learned article or in his memoirs or in gossiping with friends, unless he took appropriate steps to conceal the identity of W.'

This case reveals some important limitations on the justification based on a threat of death or serious harm to another:

(i) It must be shown that there is a real and serious risk of danger to the public.

It must be shown that the risk was of significant harm, probably of a physical kind, to a victim. Also that risk must be a serious possibility and not merely a fanciful one.

(ii) The risk must be an ongoing one.[111] The fact that there was in the past a risk to the public would not, it seems, be sufficient.[112]

(iii) The disclosure had to be to appropriate people with a legitimate interest in the matter. In *W v Egdell* the Court of Appeal approved of the disclosure to the hospital and the Home Office. A disclosure to members of the press would probably not be regarded as lawful. Although there might be cases where revealing information to the public would be appropriate (e.g. if a dangerous patient escaped from a secure hospital). Disclosure of confidential information to regulatory bodies such as the

[111] *R v Harrison* [2000] WL 1026999 held that a doctor owed no duty of confidentiality in respect of threats to kill made by a defendant. See also *R v Kennedy* [1999] 1 Cr App R 54.

[112] *Schering Chemicals v Falkman Ltd* [1981] 2 All ER 321.

GMC is permissible if to do so is necessary to enable them to ensure that the public is protected from professional misconduct.[113]

(iv) Any disclosure must be restricted to the minimum necessary to protect the public.[114] To use the example just mentioned if a dangerous patient escaped from a secure hospital, although it may be justifiable to inform the public that the patient posed a particular risk, for example towards elderly women, it would not be necessary for all of his medical history or details to be made public.

What is the position where a patient has informed his doctor that intends to kill or cause serious harm to another and the doctor decides to keep quiet about this? If the patient does go on to kill or cause serious harm can the doctor be sued? An American decision, *Tarasoff v The Regents of the University of California*[115] discusses the issue.

P was receiving therapy at a hospital in the University of California at Berkeley. He told his therapist, a Doctor Moore, that he was going to kill his former girlfriend, Tatiana Tarasoff when she returned from her holidays. The doctor informed the police who detained P but released him when he promised not to harm Tatiana. The doctor took no steps to warn Tatiana herself. On her return from holiday P killed Tatiana. The Supreme Court of California, by a majority, held that Dr Moore owed Tatiana a duty of care. Where a doctor is aware that one of his patient poses a serious danger of violence to another he incurs an obligation to use reasonable care to protected the intended victim. He had failed to do this. It is far from clear whether that decision would be followed in England and Wales. The general view seems that it would not[116] because normally in tort law someone is not responsible for the acts of a third party.[117] In *Palmer v Tees Health Authority*[118] it was held that a health authority did not owe a duty of care to a woman who was killed by a man they were caring for. One of the reasons given was that there was no way the Health Authority could foresee that their patient would kill this man. This might suggest that the case would be decided differently if he posed a risk to an identifiable individual.

2.7 Child protection

In a similar vein to the exception just mentioned confidence can be breached if there is evidence that a patient may have been abusing a child.[119] The GMC has suggested that not only may doctors make a disclosure in order to protect a child from abuse they must do so:

[113] *Re A (A Minor) (Disclosure of Medical Records to GMC)* [1999] 1 FCR 30; *Woogar v Chief Constable of Sussex Police & UKCC* [1999] 1 LMLR 335.

[114] *X v Y* [1988] 2 All ER 649.

[115] (1976) 17 Cal (3d) 358.

[116] Miers (1996); Morris and Ashead (1997).

[117] *Smith v Littlewoods* [1987] AC 241.

[118] [2000] PIQR 1.

[119] *Re M* [1990] 1 All ER 205, 213. DoH (1999: para 7.27)

> If you believe a patient to be a victim of neglect or physical, sexual or emotional abuse and that the patient cannot give or withhold consent to disclosure, you must give information promptly to an appropriate responsible person or statutory agency, where you believe that the disclosure is in the patient's best interests. If, for any reason, you believe that disclosure of information is not in the best interests of an abused or neglected patient, you should discuss the issues with an experienced colleague. If you decide not to disclose information, you must be prepared to justify your decision.[120]

This also could be justified in terms of article 8, in that the patient's rights under that article are properly infringed because to do so is necessary in the interests of others (i.e. the child).

2.8 Assisting police investigations

Perhaps surprisingly, there is no general obligation on health processionals to disclose confidential information even if requested to do so by the police.[121] There are a few specific circumstances where they must. They are bound to provide the police on request with any information that would identify a driver alleged to have committed a traffic offence.[122] Even if not specifically requested they are bound to disclose to the police suspicions that a person has been involved in terrorist activities.[123] It should be added that medical professionals should not obstruct a police investigation, but that offence will not be committed by failing to answer police questions, provided they have a lawful excuse (e.g. that the information requested is confidential).[124]

Although there are only limited circumstances in which there is a *duty to* disclose information there are circumstances in which the information *may* be disclosed. The Crime and Disorder Act 1998, section 115 permits the disclosure of confidential information to, *inter alia*, a Chief Officer of Police. However, this power should only be used where the patient has consented or there is a strong public interest for doing so.

The BMA and Department of Health[125] have suggested that doctors should considering disclosing information where all of the following are true:

- The offence is grave (e.g. murder, manslaughter, rape, hostage-taking, causing death by dangerous driving)
- The prevention or detection of the crime will be seriously delayed or prejudiced without the disclosure
- The disclosed information will only be used for the detection and prosecution of the alleged criminal

[120] GMC (2004: para 29). Although Montgomery (2002: 269–271) questions the source of the legal obligation.

[121] *Sykes v DPP* [1962] AC 528, 564 (Lord Denning).

[122] Road Traffic Ac 1988, s. 172.

[123] Terrorism Act 2000, ss. 19 and 20.

[124] *Rice v Connolly* [1966] 2 All ER 649.

[125] BMA (1988: 23–4) and DoH (1996).

- Any material released will be destroyed once it has been used.

Lord Denning in *Initial Services Ltd v Putterill*[126] appeared to suggest that disclosure of any crime committed or contemplated is permitted. If this is correct it means that a doctor who discloses information concerning a minor crime is not acting illegally, but is acting contrary to professional guidance. That said, until we have further guidance on the law in this area it is not safe to declare with confidence what the law is.

2.9 Public debate and press freedom

Can a breach of confidentiality be justified on the basis that the disclosure is in the public interest because it promotes public debate? Two cases which shows the issues well are *H (A Healthcare Worker) v Associated Newspapers Ltd* and *N (A Health Authority) and X v Y*.

KEY CASE X v Y [1988] 2 All ER 649

A newspaper discovered that two doctors were being treated for AIDS. A hospital sought an injunction to prevent the publication of the information. The newspaper accepted that it had obtained the information in breach of confidence, but argued that it was important that there was a public debate over the issue. The judge argued that the public interest (which was not to be confused with things in which the public were interested) had to be weighed against: (i) the principle that hospital records should remain confidential; (ii) the public interest that employees should not be encouraged to disclose confidential information to newspapers. In other words prohibiting the publication might deter employees passing on confidential information to newspapers in the future; (iii) the public interest in ensuring that that AIDS sufferers could use hospitals without fear that their condition will be made public. Taking these factors into account the judge concluded that the newspaper should not publish the information. The judge noted that there was already wide-ranging debate about AIDS and the information in question would add little to it.

KEY CASE H (A Healthcare Worker) v Associated Newspapers Ltd and N (A Health Authority) [2002] LLMLR 210 CA.

H, a health care professional was tested positive for HIV. The health authority (N) proposed to notify all his patients and invite them to undergo an HIV test if they wished. H sought an injunction to prevent N from notifying his patients. He argued that the risk to patients of HIV was very low and insufficient to justify a breach in his confidentiality. The *Mail on Sunday* got to hear about the dispute

[126] [1968] 1 QB 396, 405.

and H successfully applied for an injunction to prevent the publication of any details identifying him, his speciality or N. On the hearing for the full injunction Gross J upheld the ban on publishing H's identity, but would have allowed the naming of N and H's specialism. H appealed to the Court of Appeal, arguing that it would be easy for people knowing his specialism and the name of the health authority to discover his identity. The Court of Appeal held that H's name and N's identity should be kept secret. They accepted the argument that H's identity would otherwise be too readily discovered. In particular they were concerned his patients would discover the news before being contacted by N and being offered the appropriate counselling. However, H's specialism could be named, because that raised particular issues which were relevant to a legitimate debate about the risks of HIV.

It is a notable aspect of *H (a Health Care Worker) v Associate Newspapers Ltd* that the court attached particular significance to the protection of press freedom guaranteed by article 10 of the European Convention on Human Rights. This right clearly led the court to require clear harms to justify an interference with this right:

> We would view with concern any attempt to invoke the power of the court to grant an injunction restraining freedom of expression merely on the ground that release of information would give rise to administrative problems and a drain on resources. Such consequences are the price which has to be paid, from time to time, for freedom of expression in a democratic society.

In weighing up the freedom of expression and protection of privacy in a case where medical records have been improperly acquired the court should consider *both* the interests of the individual patient and the interests of the hospital in ensuring the confidentiality of its records.[127]

2.10 For the best interests of an incompetent person

If a person is incompetent then it is generally thought that it is permissible to disclose confidential health information to those caring for her or others if that was necessary for her proper care.[128] However this exception should be interpreted strictly. As the BMA have stressed just because a patient is incompetent this should not lessen the protection that is accorded to her right of confidentiality.[129]

2.11 Discovery

If a person is bringing or plans to bring legal proceedings against another she can apply for all relevant information to be disclosed. However this is not an absolute right. In *D v*

[127] *Ashworth MGN* [2002] UKHL 29; [2002] 4 All ER 193.
[128] *F v W Berkshire HA* [1989] 2 All ER 545.
[129] BMA (2004: 178).

NSPCC[130] the plaintiff sought from the NSPCC documents indicating the name of the person who had alleged that she had been committing child abuse. The court refused to order disclosure of the information. It was felt that it was necessary to weigh up the plaintiff's interest in discovering her accusers, so that she could if appropriate bring legal proceedings against them, with the public interest in encouraging people who have suspicions about child abuse to alert appropriate authorities, without fear that doing so could lead to legal proceedings being taken against them. The balance fell against ordering disclosure. The same approach might be taken if a person was seeking another's medical records for the purposes of using it in litigation: would the interest in protecting confidentiality outweigh the importance of enabling a person to have access to relevant documents in the course of legal proceedings. The reasoning in *D v NSPCC* would not be directly applicable because the issue there was a special immunity known as 'Crown Immunity' which applied to bodies acting in the public interest. Nevertheless a similar approach may well be adopted by the courts when considering infringement of an individual's rights of confidentiality.

If a health professional is called to court in a case as a witness and is asked about confidential information then he or she can ask to be permitted to decline to answer the question on the basis that it would involve breaking confidence. However, if the judge states that the information must be provided it would be a contempt of court of the professional not to provide the information. In *AB v Glasgow and West of Scotland Blood Transfusion Service*[131] a Scottish court refused to require a doctor to name a donor who has supplied infected blood as part of a blood donation. The concerns about the impact of discouraging blood donation was held to outweigh the importance of the information for the case.

2.12 Good faith disclosure

The Court of Appeal in *R v Department of Health ex p Source Informatics Ltd*[132] suggested that there is only an breach of confidence if the breach affects the conscience of the discloser.[133] In other words if the revelation of the secret information is in good faith then there is no breach of confidence. It is not clear, however, that this represents the law. It does not sit easily with *Swinney v Chief Constable of Northumbria Police*[134] which suggest that a breach of confidence does not need to be deliberate and can be negligent.[135] More significantly Lord Hoffman in *Campbell v MGN* in the House of Lords stated that the modern understanding of breach of confidence was that it was not based on a 'good faith' requirement imposed upon the recipient of the information, but

[130] [1978] AC 171.

[131] (1989) 15 BMLR 91 (Scottish Court of Session (Outer House)).

[132] [2000] 1 All ER 786.

[133] The role of conscience in breach of confidence was also emphasized in *Campbell v MGN* in the Court of Appeal [2003] QB 633 and *Stephens v Avery* [1988] 2 All ER 477.

[134] [1996] 3 All ER 449.

[135] See also Fennell (2000) who questions this part of the judgment.

rather it focussed on the protection of human dignity and autonomy of the person the information concerned.[136]

2.13 Other public interest reasons

The exceptions mentioned so far can be said to be justifiable in the public interest. There may be in addition to those already discussed a 'catch all exception' that a breach of confidence can be justified in the public interest. The GMC give an example of 'where a colleague, who is also a patient, is placing patients at risk as a result of illness or other medical condition.'[137] When relying on the general public interest the medical professional must be persuaded that it is necessary to reveal non-anonymized data and that it is not practical to obtain the consent of the patient.[138]

In *R v Crozier*[139] a psychiatrist instructed by the defendant in an attempted murder case disclosed his report to the prosecution after a judge sentenced the defendant to prison, not having been told of the report. Once the judge was informed about the report the defendant was sentenced to a hospital order and orders were made under the Mental Health Act 1983. The court held this disclosure was justified in the general public interest in ensuring appropriate sentences were imposed in criminal cases.[140]

2.14 Special statutory provisions

There are special statutory provisions which permit or even require confidential information to be disclosed. To give a couple of examples: a doctor treating a drug addict must give details about the person to the Home Office;[141] and the Public Health (Control of Disease) Act 1984 states that cholera, plague, relapsing fever, smallpox and typhus shall be notifiable diseases which means that if a doctor finds a patient with such a disease she must notify the Government. Similarly some kinds of venereal disease[142] and food poisoning are notifiable. The Government has been under pressure to add HIV/AIDS to the list of notifiable diseases, but has declined to do so.[143] The argument is that HIV/AIDS is nothing like as infectious as, for example, cholera, and indeed with responsible behaviour poses no risk to others. It is therefore in the public interest to encourage people to receive medical treatment for suspected AIDS and not be deterred by any mandatory reporting requirement. Controversially details of terminations of pregnancies under the Abortion Act 1967 must be given to the Chief Medical Officer.[144]

[136] *Campbell v MGN* [2004] UKHL 22, para 51.

[137] GMC (2004: para 37).

[138] GMC (2004: para 1).

[139] (1990) 12 Cr App R (S) 206.

[140] Disclosure of medical reports might also be justifiable in order to protect the economic well-being of the country: *MS v Sweden* (1997) 45 BMLR 133.

[141] Misuses of Drugs (Notification of Supply to Addicts) Regulations 1973, SI 1973/799.

[142] *Lee v South West Thames RHA* [1985] 2 All ER 385.

[143] See Keown (1989) for a summary of the arguments.

[144] Abortion Regulations 1991, SI 1992/499.

Since 2002 only a patient's NHS number, date of birth and full postcode are required, not her name.[145]

Section 60(1) Health and Social Care Act 2001 permits the disclosure of medical information for research purposes without a patient's consent. This provision provides:

> The Secretary of State may by regulation make such provision for and in connection with requiring or regulating the processing of prescribed patient information for medical purposes as he considers necessary or expedient—
>
> (a) in the interest of improving patient care, or
>
> (b) in the public interest.

This is a controversial provision because potentially it provides a significant inroad into protection of medical confidentiality. Regulations under the Act state 'Anything thing done by a person, that is necessary for the purposes of processing patient information in accordance with these Regulations shall be taken to be lawfully done despite any obligation of confidence owed by that person in respect of it.'[146]

Much depends on what kind of regulations will be issued by the Secretary of State. He or she must consult with a Patient Information Advisory Group before issuing any regulation.[147]

The Patient Information Advisory Group[148] has the job of overseeing arrangements created under section 60. It has made it clear that section 60 will not be allowed to be used just in order to make access to medical data easier. It will have to be shown that there is no other practical way to get to the data and that it is not possible to use anonymized data. Between December 2001 and June 2003 there were 65 applications and approval was given to 42.

Section 60 has been criticized. The BMA has complained that it is 'very general' and more guidance is required on how to apply it. It is justified by others on the basis that if large scale research needs to be carried out it is not practical to obtain the consent of each and every person. If that was done and only the information of those who consented could be used this would skew the sample. On the other hand researchers have complained the procedure to obtain approval to carry out large scale studies are 'sluggish' and an improper restriction on research.[149]

2.15 Extent of disclosure

One point which has already been emphasized at several points bears repeating and that is that even if there is a justifiable ground for disclosure it must be shown that:

[145] DoH (2002).

[146] Health Service (Control of Patient Information) Regulations 2002, SI 2002/1438.

[147] See Health Service (Control of Patient Information) Regulations 2002, SI 2002/1438.

[148] Patient Advisory Group (2003).

[149] Turnberg (2003).

(i) The person to whom the disclosure was made was an appropriate person.[150] So although in a certain case disclosure to the police may have been justified if the disclosure was to a journalist this may be unlawful.

(ii) The disclosure was to the minimum amount necessary under the justification. In other words if anonymized disclosure would have adequately protected the public interest then only non-anonymized disclosure is permitted.

3 The Data Protection Act

The Data Protection Act 1998[151] covers the processing of personal data. The Act is not restricted to computerized records; it covers all personal data stored in systems (be they electronic or on paper) that enable information about someone to be readily accessible. At the heart of the Act are eight cardinal principles which are set out in Schedule 1, Part 1 of the Act:

1 Personal data shall be processed fairly and lawfully and, in particular, shall not be processed unless—

   (a) at least one of the conditions in Schedule 2 is met, and

   (b) in the case of sensitive personal data, at least on of the conditions in Schedule 3 is also met.

2 Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.

3 Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.

4 Personal data shall be accurate and, where necessary, kept up to date.

5 Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose for those purposes.

6 Personal data shall be processed in accordance with the rights of data subjects under this Act.

7 Appropriate technical and organizational measures shall be taken against unauthorized or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.

8 Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensure an adequate level of

[150] In *Woolgar v CC of Sussex Police* [1999] Lloyds Rep Med 335 the police contacted the UKCC (the nurse's professional body) after they had concerns over her behaviour.

[151] The Data Protection Act 1998 was passed to give effect to the European Directive on Personal Data 1995 (EC Directive 95/46/EC).

> protection for the rights and freedoms of data subsection relation to the processing of personal data.

Health records are classified as 'sensitive personal data' and is subject to special protection. A health record is defined as:

> any record which:
>
> (a) consists of information relating to the physical or mental health or condition of an individual, and
>
> (b) has been made by or on behalf of a health professional in connection with the care of an individual[152]

All information in health records is regarded as sensitive personal data, whether it relates to minor injuries or much more intimate information.[153] Sensitive personal data can only be 'processed' (e.g. consulted or used) if a series of special conditions are met. These include[154]:

(a) The patient has given explicit consent to the information being used.

(b) It is necessary to process the information to protect the vital interests of the patient.

(c) Where the data is in the public domain.

(d) A health care organization or professional needs to use the information to obtain legal advice or in the course of legal proceedings.

(e) The processing of the information is necessary for the purposes of statutory or government functions.

(f) It is necessary for medical purposes and the information is used by a healthcare professional.

(g) Processing of medical data or data relating to ethnic origin for monitoring purposes.

(h) Processing in the substantial public interest, necessary for the purpose of research whose object is not to support decisions with respect to any particular data subject otherwise than with the explicit consent of the data subject and which is unlikely to cause substantial damage or substantial distress to the data subject or any other person.[155]

It is the responsibility of the 'data controller' to ensure that these obligations are complied with. However all those who use protected information are required to comply with the terms of the legislation. Anyone who obtains or discloses information without the consent of the data controller commits an offence.[156] If a person has suffered

[152] S. 68(2).

[153] Information Controller (2002).

[154] The full list is to be found in Data Protection Act 1998, Schs 1 and 3.

[155] The Data Protection (Processing of Sensitive Personal Data) Order 2000 added (g) and (h).

[156] S. 55.

damage or loss as a result of a violation of the Data Protection Act he or she can receive compensation. There is also an obligation on health organizations to protect the security of health records. The Information Controller has the power to issue an enforcement notice requiring specific steps be taken to ensure compliance of data.[157] Individuals can ask the Information Controller to assess whether the Act is being complied with.[158] It is a criminal offence to fail to comply with a notice.[159] The Information Controller also had the function of preparing good practice guidance.[160]

4 Problem issues

We now look at some particular areas in relation to confidentiality which have proved particularly controversial.

4.1 Genetic information: Informing relatives

Genetic information has become an increasingly important and the extent to which it should be kept confidential is a highly topical issue.[161] Consider the following two scenarios because they indicate why the issue can be complex:

(i) A couple are considering having a child but are aware that there may be genetic diseases in the family history. They seek medical advice on what risks there are that any child of theirs will inherit a condition. The doctor to properly advise them will need the medical history of their parents. If the couple's parents refuse to co-operate, can the doctor access the parents' notes so as to advise the couple?

(ii) In treating X a doctor discovers that X suffers from a genetically inherited illness and therefore it is likely that X's relatives do too. The doctor wishes to advise the relatives of that risk, but X objects to this. If the doctor went ahead and informed the relative the doctor would be infringing X's rights to confidentially?

It is notable that in both these cases if the doctor maintains confidentiality he or she is not thereby putting people at risk of harm, rather he is she is denying them the option of treatment or advice which might otherwise have been available. Montgomery[162] suggests that going back to first legal principles the law does not normally require people to provide benefits to others, but simply not to harm them. This might suggest that the law would require confidentiality to be preserved. He goes on to suggest, however, that

[157] S. 40.

[158] S. 42.

[159] S. 55.

[160] S. 51(3). Information Commissioner (2002). See also Health and Social Care Act 2001, s. 60 which permits the making of regulations in relation including to using information to pursue the public interest where the information is kept anonymous.

[161] Pullen (1990); Suffield Council on Bioethics (1993); Genetic Interest Group (1998).

[162] Montgomery (2003: 277).

this might be a situation where the law should depart from its normal approach, and adopt a less individualistic approach. With similar ideas in mind Loane Skeane[163] has contrasted two approaches that could be taken to this topic:

(i) A legal approach. This emphasizes individual rights of privacy of particular patients.

(ii) A family approach.[164] This focusses on the care of patients with genetic illness. It places less weight on individual rights and emphasizes the concerns of the community and families. Patients should be treated as members of a family, not as isolated individuals.

One question which is immediately raised is whether the issues surrounding genetic information is any different from other medical information. Skeane suggests a number of differences including the following:

- for genetic tests to be accurate it is necessary to test members of the patient's family;
- the issue of consent to the tests is complex because the results will not be certain and will be predictive of an illness perhaps quite some time in the future;
- there may be significant social and legal consequences which flow from a test;
- the result of the test may have significance for other members of the family.[165]

Gostin and Hodge[166] are critical of any attempt to provide special protection for genetic information. They argue that a genetic predisposition to a particular illness is no different from a predisposition to an illness that a person might have from other causes. They go on to argue that it would be quite wrong if the legal position in relation to a woman whose breast cancer was linked to genetic factors was any different from a woman whose breast cancer was due to other factors. One response to this is that it is not the position of the woman which is different, but the claims, if any, that can be made by her relatives.

The courts are yet to discuss the issues relating to genetic confidentiality and there may be legislation in the area. So all it is possible to do at the moment is outline a number of ways the law could address the issue:

4.1.1 *The traditional confidentiality approach*

It could be argued that issues surrounding genetics should be addressed in line with the normal rules on breaching confidentiality.[167] This would suggest that only where there is a high risk of significant harm to another is it proper to breach confidentiality.[168] So the arguments in favour of informing a patient's relatives are stronger the greater the risk of

[163] Skeane (1998).

[164] Skeane (1998) described this as a medical approach but in Skeane (2001) stated that she preferred the term family approach.

[165] But see Mason McCall Smith Laurie (2001: 207) for an argument that other kinds of medical test results can also carry significance for family members.

[166] Gostin and Hodge (1999).

[167] Bell and Bennett (2001).

[168] Grubb (1999) suggests that the courts at some point will recognize a legal duty on doctors to tell relatives in such a case.

the relative suffering from the illness; the greater its severity; and the more likely it is that having the information will enable the relative to receive effective treatment for the condition.[169]

Laurie[170] has suggested in considering disclosure of genetic information to a relative the following factors should be considered:

- the availability of a therapy or cure
- the severity of the condition and the likelihood of onset
- the nature of the genetic disease
- the nature of any further testing which might be required
- the nature of the information to be disclosed
- the nature of the request (for example, testing for the individual's health or for diagnostic purposes for a relative)
- the question of whether disclosure can further a legitimate public interest
- the question of how the individual might react if offered unsolicited information (for example, whether any advance directive has been made).

Critics of the traditional approach claim that it is individualistic and fails to take into account that we are not isolated people but live in a web of family relationships.[171] Most people would want family members to whom they were close to be told of medical information that was relevant.[172] Informing family members will support and encourage family bonds, whereas the individualist traditional approach threatens them. However, it should be born in mind that what we are discussing here is whether a doctor should provide information to a patient's family against the patient's wishes. Where the patient is happy for her family to be informed there are no particular legal difficulties.

4.1.2 *A Human Rights Act approach*

A similar solution could be reached if the issue was examined from the perspective of the Human Rights Act. A patient would have the right for his genetic information to be kept secret under article 8,[173] but that right could be interfered with if necessary to protect the interests of others as set out in article 8(2). It should be emphasized that the infringement can only be justified under article 8(2) if it is in accordance with the law. So anyone seeking to rely on article 8(2) to justify an interference in someone's rights of confidentiality would need to point to a statutory or common law permission to do so. It is likely that only if another was going to suffer a serious harm would the breach of private life involved in breaching genetic confidentiality be justified. It might be argued that as genetic information might be regarded as even more private, more connected with the

[169] Ngwana and Chadwick (1993).

[170] Laurie (2000).

[171] Gilbar (2004).

[172] Benson and Britten (1996).

[173] *A London Borough Council v (1) Mr & Mrs N* [2005] EWHC 1676.

most intimate part of person, that even stronger reasons are required to justify its disclosure than is normally required to justify disclosure of medical information.

4.1.3 *The right not to know*

Laurie has emphasized that as well the patient having a right of confidentiality the court should also take into account that the relative could claim a right not to know the information. The 'right not to know' has been recognized in the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, of which article 10(2) 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.

At first, the notion of a right not to know sounds strange.[174] But imagine this: you have a 10 per cent chance that you will develop a genetic disease to which there is no known cure or treatment. If you are told this your life might be blighted by the knowledge, living in terror of this illness, seeing signs of it in every twinge or strange feeling in your body and you might never develop the disease. With this in mind you might, quite rationally, decide that it would have been better for you not to know of this genetic risk. It is, therefore, rational for someone to say 'I do not want to be told of risks of illnesses, unless that knowledge will enable me to take preventative action.'[175] Of course, it would also be rational to say that you would want to know of risks so that you can plan your life accordingly.[176] The difficulty is, of course, that most people do not think about the issue. We end up usually trying to guess whether or not a person would want to be told about a certain risk. To overcome this problem Laurie proposes that we focus on the right of privacy rather than a right not to know.[177] This idea is one we will look at later.

4.1.4 *A property approach*

A very different approach would be to say that that a person's genetic data belongs not just to themselves, but also to their relatives.[178] There is some research suggesting that this is how such information is understood by members of the public.[179] After all, a person's genetic information can say as much about their relatives, as it does about themselves. In the terms of the Data Protection Act 1998 a daughter, for example, can

[174] Takala (1999).

[175] See Andrews (2001: 31–40) and Hoff and Wuflsberg (1995) for evidence that after being informed of a risk of serious illness patients suffer psychological illness. One study (Almqvist (1999)) found that suicide rates among those informed they have Huntingdon Disease is 10 times higher than the United States' average. Levitt (1999) studies the impact on the sense of self caused by knowledge of a predisposition towards a particular illness.

[176] Hietala (1995), Hayden (1991).

[177] Laurie (2000). See also Ngwena and Chadwick (1993).

[178] *R v Department of Health ex p Source Informatics Ltd* [2000] 1 All ER 786 suggests that a patient does not 'own' his or her medical information.

[179] Kent (2003).

claim that information held in connection about her mother is information held about her.

4.1.5 *A duty approach*

Another solution would be to insist on the preservation of medical confidentiality, but place a legal duty on the person tested to inform his or her family of any risks they face in the light of the test. The NHS could consider even make it a condition of genetic testing that the patient agree that relatives will be informed of any relevant information.[180] However, the approach suffers from the difficulty that we do not normally require people to bear such a duty to warn relatives of dangers to their health.[181] There is no obligation on someone to warn their sister of the dangers of smoking. Gilbar[182] has suggested that before testing is carried out all family members who may be affected should agree whether or not they wish to be informed of the results.

4.1.6 *The public health approach*

Gostin and Hodge[183] have argued that the collection, study and dissemination of genetic information can achieve important public health goals. The more we can learn about the genetic causes of various diseases the more we can do to put in place programmes of education or treatment to prevent or ameliorate these illnesses. There are therefore dangers that in treating genetic information as some kind of especially privileged information we shall lose out on a host of gains. As they ask:

> '[I]s the value of collecting genetic information so important to the achievement of communal goods that the law ought not promise absolute or even significant levels of privacy? Perhaps the law should simply require that genetic data be acquired, used, and disclosed in orderly and just ways, consistent with the values of individuals and communities.'

4.2 **Genetic privacy: Insurance**

Another controversial issue concerning genetic information is its use for insurance purposes.[184] An insurance company offering someone life insurance would dearly want to know genetic information about that person so that a precise calculation can be made as to whether they are a good or a bad risk for life insurance purposes. However, if genetic information were to be made available to insurers this would mean that some people would, in effect, be unable to acquire life insurance. This would also probably mean that they would not be able to take out a mortgage. Being denied life insurance, then, can have a severe impact on someone's life.[185] Concerns of this kind led the Human Genetics

[180] Genetic Interest Group (1998).

[181] King (2000).

[182] Gilbar (2004).

[183] Gostin and Hodge (1999).

[184] McGleenan (2000).

[185] Laurie (2002: 138).

Commission in May 2001 to impose a three year moratorium preventing insurers seeking access to genetic test results,[186] where the figure involved was less than £500,000. The Association of British Insurers, who represent the majority of insurance companies has voluntarily agreed a five year ban on requesting genetic information for other policies.[187] The Human Genetic Commission has asked the government to pass legislation specifically to protect genetic privacy and outlaw discrimination on the grounds of genetic make-up.[188]

In many ways the issue over insurance depends on what values should underlie life insurance. Is our society one which is willing for the majority of people to pay slightly higher life insurance premiums, so that genetic information can be kept confidential? Or do we believe that each person is entitled to be assessed for life insurance on their own merits? This will mean that those with genetic make-up predisposing them to various illnesses will have to pay much higher premiums, and those with 'healthy' genetic make-up paying slightly lower premiums.[189] One MORI poll suggests that four out of five members of the general public thought that genetic information should not be used for insurance purposes.[190]

4.3 HIV status: Informing partners

Of course if a patient is tested HIV positive his physician will recommend that s/he avoid unprotected sexual intercourse, and other practices that could involve the transmission of AIDS.[191] But what if the patient refuses to agree and refuses to inform her/his partner of the HIV status? In such a case should the physician inform the partner of the patient's status without her/his consent? To do so would, of course, be a clear breach of confidence, but may enable the partner to take precautions which would avoid her/him acquiring the virus. Not surprisingly, this is a highly controversial issue.[192]

Montgomery[193] suggests we apply the basic principles on confidentiality. As HIV infection is a serious harm it is justifiable to reveal a person's HIV status if (a) there is a real risk to the person to be informed and (b) the disclosure is the only practical way of protecting them. The General Medical Council has advised that informing others who are at serious risk of infection from a patient is justifiable, even if the patient refuses to

[186] There is one exception and that is for tests relating to Huntington Chorea. DoH (2000).

[187] Laurie (2004: 137).

[188] Disability Discrimination Act 1995 does something to protect discrimination on the grounds of genetic background. At present there is no evidence that people are discriminated against in the area of insurance in relation to genetic make-up: Low et al (1993).

[189] Rothstein (1998).

[190] MORI (2001 para 7.2)

[191] Some studies indicate promises made by a patient that he will tell his partner cannot be relied upon: Landis, Schoenbach and Weber (1992).

[192] See for example BMA (2004); Gostin and Hodge, Jr. (1998): DoH (1993); GMC (1993), Boyd (1992) and Gillon (1987).

[193] Montgomery (2003: 269).

consent to others being informed.[194] However, their advice is put in terms of it being permissible to tell others, rather than there being a duty to tell others.[195] It is arguable that this puts a doctor's duty in too weak terms.[196] Although normally one person is not liable in tort or criminal law for a wrong committed by another,[197] now there is a duty on the state under the Human Rights Act to protect citizens lives under article 2 and to protect citizens from torture or inhuman or degrading treatment under article 3. This may *require* the NHS to inform relatives who are known to be at risk of being infected with HIV.[198] But is it reasonable to permit disclosure of confidential information in this case when so often the fact a person could possibly infect others (e.g. because they have chickenpox) is not disclosed?

What is often overlooked in this debate is that it is a serious criminal offence for someone who is aware s/he is HIV positive to infect a partner by engaging in sexual relations without informing her/his partner of the risk.[199] There seems an arguable case for saying that a doctor should 'shout' a warning to protect a victim from a foreseeable crime.[200] Another way of seeing the issue is to argue that the commission of the offence (or perhaps threat to commit the offence) by the patient justifies the loss of a right of confidentiality. However, a court might decide that if the doctor was convinced there was a serious risk to the girlfriend s/he ought at least have informed the police.[201] The issue might also be regarded differently if the partner is also the doctor's patient.[202] Feminists in particular have been keen to argue in favour of a right to inform third parties. It has been claimed that women are more likely than men to be the ones who are not informed by their HIV positive partners.[203] Although there are also concerns that revealing HIV status is likely to lead to domestic violence.[204] Further is society entitled to place obligation on HIV positive people and infringe their confidentiality rights, given its inadequate support for them?[205]

The case against the doctor informing the partner is an argument that confidentiality must be taken seriously. In our society someone's HIV status can be particularly sensitive information.[206] The revelation by someone of their HIV status to their partner is an

[194] Although a doctor should inform his patient if he has done this: GMC (1997).

[195] This was said to be the law in Jones (1996: para 2.77–2.86).

[196] See *Reisner v Regents of the University of California* [1997] Med L Rev 25. For further discussion see Jones M (1990).

[197] *Smith v Littlewoods* [1987] 1 All ER 710.

[198] E.g. *Osman v UK* [1999] 1 FLR 193.

[199] *R v Dica* [2004] EWCA Crim 1231.

[200] Khan, Robson and Swift (2002: 13) argue that a doctor may, but does not have to, inform the partner.

[201] Brazier (2003: 71).

[202] Mason, McCall Smith and Laurie (2001: 252).

[203] Gostin and Hodge (1998).

[204] North and Rothenburg (1994).

[205] Holm (2001).

[206] This was accepted by the European Court of Human Rights in *Z v Finland* (1997) 25 EHRR 371.

intimate matter which should be left to the individuals themselves Another concern focusses on the practical issues. Mason, McCall Smith and Laurie argue:

> The crucial dilemma here is whether relaxation of the confidentiality rule would lead to failure to seek advice and treatment and hence to the spread of the disease, or whether the imposition of absolute secrecy improperly denies others the opportunity to avoid the risk of exposure to infection or the benefits of early therapy where exposure has occurred.[207]

The argument could be made that although warning the partner may save that person's life if the informing of partners becomes standard practice that might deter people from seeking medical advice in connection with HIV which in the long run might lead to a loss of even more lives.[208]

A slightly different scenario involves health care workers who are HIV positive.[209] It is generally thought that health workers who are HIV positive pose a very low risk to patients and therefore disclosure of her status to the public is not justified.[210] However if the health care worker is a surgeon there is a risk with some kinds of operations that if the surgeon cut her-/himself then the disease could be spread. In such a case the GMC advises a surgeon to avoid such operations and if a surgeon does not then his or her colleagues must inform the relevant regulatory authority and appropriate person in the health worker's authority.[211]

4.4 Domestic violence and child abuse

What if a patient reveals that she or her children are being the victims of abuse from her partner?[212] There seems near universal agreement that in the case of child abuse the doctor must break confidence if that is necessary to protect the children. Where the adult patient is her- or himself the victim of abuse the position is more debatable. The advice from the GMC is:

> If you believe a patient to be a victim of neglect or physical, sexual or emotional abuse and that the patient cannot give or withhold consent to disclosure, you must give information promptly to an appropriate responsible person or statutory agency, where you believe that the disclosure is in the patient's best interests. If, for any reason, you believe that disclosure of information is not in the best interests of an abused or neglected patient, you should discuss the issues with an experienced colleague. If you decide not to disclose information, you must be prepared to justify your decision.[213]

[207] Mason, McCall Smith and Laurie (2002: 249).

[208] Mikolowski (2004: 29).

[209] See Burrows (2001) for a general discussion about health care workers who pose a risk to patients.

[210] There has been only one clear case of a health care worker infecting patients in the world: Mason McCall Smith Laurie (2002: 250).

[211] See now the guidance in DoH (2002b: chapter 8).

[212] Jecker (1993).

[213] GMC (2004: para 29). This passages is approved by the BMA (2004: 195).

4.5 Confidentiality and child patients

The issue of confidentiality and children was considered in detail in chapter 3.[214] Young people aged 16 or 17 are regarded as adults for purposes of consent to treatment and are therefore entitled to the same duty of confidence as adults.[215] The Data Protection (Subject Access Modification)(Health) Order 2000[216] states that competent children can prevent their records being disclosed to parents, where they are able to appreciate the nature of the application for access to the records.

Children under 16 who have the capacity and understanding to take decisions about their own treatment are entitled also to decide whether personal information may be passed on and generally to have their confidence respected (e.g. they may be receiving treatment or counselling which they do not wish their parents to know about). In other instances, decisions to pass on personal information may be taken by a person with parental responsibility in consultation with the health professionals involved.[217]

More problematic are cases where the child who is not competent to consent to treatment asks the doctor not to tell his or her parents. There is no clear case law authority. There is much to be said for the view[218] that the key question is whether the child is competent to reach a decision about confidentiality. Just because a child is not competent to decide about a medical treatment does not mean that the child is not competent enough to reach a decision about whether or not his or her parents should be informed. If the child is competent to decide that the parents should not be involved the doctor must follow their wishes. However, it has also been suggested that if a child is incompetent to reach the medical decision then the child is incompetent to make the medical decision then there is no duty of confidentiality. Kennedy[219] supporting this view argues that the basis of the obligation of confidence is about enabling autonomous decision-making. If the child is unable to make the decision then autonomy is not at issue. However, there is an argument that confidentiality is not about autonomy but privacy rights and these rights exist whether or not the person is autonomous.[220]

4.6 Medical research

The use of medical information has been mentioned already. The basic approach is that where possible consent of patients involved should be obtained.[221] Where that is impractical (for example where a large sample is required) then anonymized data should

[214] For a discussion of confidentiality issues and patients suffering mental illness see Cordess (2001).

[215] *Torbay Borough Council* v *MGN* [2003] EWHC 2927 (Fam). Although research by Rae, Sullivan, Razo, George and Ramirez (2002) suggests that American Psychologists are willing to break confidence in relation to adolescent patients far more readily than they would be in respect of adults.

[216] SI 2000/343, reg. 5.

[217] DoH (2004: 4.10).

[218] Montgomery (1987).

[219] Kennedy (1991: 111–17).

[220] Loughrey (2003).

[221] Medical Research Council (2003: 9).

be used. Only those personal identifiers (e.g. postcode) which are essential to the research should be in the data. MRC has legal advice that under common law it may be permissible to disclose confidential information for research purposes considering the following factors: necessity (there are no other ways of doing the study); sensitivity (was it particularly sensitive information?); importance of research; safeguards (e.g. disclose to small group as possible); independent review; expectations (have people been given the opportunity to object, if not, consent?). Interestingly there are also complaints from some in the research community about the poor quality of medical notes that are kept by the NHS.[222]

5 Legal remedies in confidentiality cases

Few cases on confidentiality appear in the law reports. This is primarily because of the limited nature of the remedies available.[223] There are basically two on offer:

- Damages
- An injunction to prevent publication.

The problem is that damages are only rarely available if there has not been a financial loss to the patient. However, rarely is there a pecuniary loss to the patient.[224] The revelation of medical information may cause embarrassment and loss of social standing, but rarely financial loss. Notably in the *Naomi Campbell* case only £2,500 damages plus £1,000 aggravated damages were awarded. Injunctions to prevent publication are only useful where it is known that the information is about to be revealed. In most cases the patient only learns of the breach of confidentiality when it is too late. Even where it is not too late the claimant will face an uphill task persuading the court that his or her right to respect for private life justifies an infringement of the freedom of the press. It may be argued that the present inadequacies of legal remedies are incompatible with an individual's rights under article 6 and 8 of the ECHR and so open to challenge through the Human Rights Act 1998.

If someone does breach confidentiality it is more likely that the remedy against them will be disciplinary procedures brought by their employers and professional bodies. For such procedures there is no need to show that the patient suffered a financial loss as a result. It has been suggested that the fact that confidentiality is widely respected is not the availability of legal remedies, but rather the wide spread acceptance of its ethical basis among those working in medicine.

[222] Medical Research Council (2003: 5).

[223] Stauch, Wheat and Tingle (2002: 260).

[224] *Cornelius v de Taranto* [2001] 68 BMLR 62.

6 Access to information

A doctor must maintain medical records as part of care for his or her patients. So far we have been discussing the obligation on doctors to keep a patient's records secret. But a patient may also want to see the information kept by him or her. There is no common law right to see your health care information,[225] but there are various statutory rights to see the information.

6.1 The statutory provisions of access to records

Data Protection Act 1998 is, by far the most important piece of legislation governing this area, but others will be briefly mentioned first. It should also be noted that article 8 of the ECHR protects the right of access to medical records and therefore legislation should be interpreted in a way which is compatible with that right.[226]

1 Supreme Court Act 1981. If a person has commenced or is likely to commence litigation which has some prospect of success then they have a right to 'discovery' of relevant evidence, including documents. These can include medical records. If disclosure would harm a patient then they can be shown only to the patient's medical advisers.[227]

2 Access to Medical Reports Act 1988. This Act applies to reports supplied by a medical practitioner for the purposes of insurance or employment. The subject of such a report has the right to see them, veto their release, and to append comments if they believe the reports are inaccurate. Doctors are entitled to refuse access if there are concerns that to do so would be likely to cause serious harm to the physical or mental health of the person seeking it or to others; or to protect a doctor's informant.

3 Access to Health Records Act 1990. The 1990 Act gives right of access to patients to all manual health records since 1 November 1991. The 1998 Data Protection Act has in fact rendered the 1990 Act obsolete, except in relation to deceased persons, who are not covered by the 1998 Act.

4 Data Protection Act 1990. Patients have rights of access to their health records under sections 7 and 8 of the Data Protection Act 1998. A person can discover if their personal data is being processed, a description of the data, the purposes for which it is being processed and the classes of people to whom it will be disclosed. Most significantly they are entitled to a copy of their records in an 'intelligible form'. This includes, where necessary, an explanation of any terms used.[228] Once they have seen their records

[225] *R v Mid-Glamorgan FHSA ex p Martin* [1995] 1 All ER 356, criticized in Dermot Feenan (1996). See also *Breen v Williams* (1996) 70 ALJR 772 and *McInerney v MacDonald* (1992) 93 DLR (4th) 415 for Australian and Canadian decisions providing alternative approaches to rights of access to medical records.

[226] *McGinley and Egan v UK* (1998) 27 EHRR 1.

[227] S. 33(2).

[228] S. 8(2). In some areas patients are entitled to access their records via the internet (BBC Newsonline (2003).

patients are entitled to require the data controller to stop processing the information if to do so would cause substantial and unwarranted distress to the patient or another.[229] The patient has the right to have the information rectified if it is wrong.[230]

There are two important limitation on the right of access under the Data Protection Act and they are:

(i) Where the disclosure would cause serious harm to the physical or mental health of the patient or another.[231] A health care professional must confirm that this applies. The BMA guidance suggests that it will be 'extremely rare' for this exception to apply.[232]

(ii) If the data disclosed would reveal information about another person. So if on a man's medical records there was a statement about his wife's concerns about him that section of the record could not be revealed.

Normally, of course, another person cannot use the Act to obtain the record of another. However a parent with parental responsibility can obtain the records of their child or a person managing the affairs of an incompetent person unless the patients have provided information in the expectation that it will not be disclosed. So if a child has seen a doctor on her own and talks on the basis that her parents will not find out what she says then this need not be disclosed.

The leading case on common law rights of access to medical records is the following:

KEY CASE R v Mid Glamorgan Health Services ex p Martin [1995] 1 All ER 356

Martin sought from the medical authorities all his personal health and social work records which had been made while he had been a patient at a number of different hospitals. The hospitals concerned were willing to disclose the records to Mr Martin's medical advisers but not to him directly.

It was held by the Court of Appeal that health authorities and doctors owned the medical notes. They could deny a patient access to the notes if that was in his or her best interests. This might be, for example, if disclosure could be detrimental to the patient's health. The offer to disclose the notes to Mr Martin's medical advisers was the most that could be expected. Sir Roger Parker LJ stated:

> I regard as untenable the proposition that, at common law, a doctor or health authority has an absolute property in medical records of a patient, if this means, which it appears to do, that either could make what use of them he or it chose. Information given to a doctor by a patient or a third party is given in confidence and the absolute property rights are therefore necessarily qualified by the obligations arising out of that situation.

[229] S. 10.
[230] S. 14.
[231] Data Protection (Subject Access Modification) (Health) Order 2000 413, art 5.
[232] BMA (2004: 217).

But he regarded as equally untenable that a patient had an unfettered right of access to his or her records. He then stated:

> In my view the circumstances in which a patient or former patient is entitled to demand access to his medical history as set out in the records will be infinitely various, and it is neither desirable nor possible for this or any court to attempt to set out the scope of the duty to afford access or, its obverse, the scope of the patient's rights to demand access. Each case must depend on its own facts.

The lawyers were only permitted to use the documents for the purposes of advising on and undertaking legal proceedings.

6.2 Should there be a right to see one's medical records?

Those who support such a right claim four particular benefits:[233]

(i) The accuracy and general quality of records would improve. Certainly there are concerns about the quality of information in medical records.[234] If a patient could check records, then this would be one way of improving the accuracy of records. It might also means that the records would be more efficiently kept and would not include inappropriate comments about patients.[235] The press is often full of reports of offensive remarks being made in people's medical records. The BMA records a case where a medical record which original referred to a patient as a 'silly old bat', although this was altered to read 'still holds bottle'.[236]

(ii) Relief of patient's anxiety. Some patients are convinced that they are suffering from illnesses that they are not or that their doctors are hiding the truth from them. A right to access their health information may allay such fears.

(iii) Improve communication. If patients are entitled to see their health care information then the records will need to be presented in a clear way which is readily understandable to patients. This might be in the best interests of everyone.

(iv) Increase trust. Openness in dealings between patients and their doctors may persuade patients to be more open with doctors and doctors more open with patients.

There are, however, those who are opposed to opening up medical records.[237] It is argued that inevitably they contain complex medical terminology and too easily lead to misconceptions and may even exacerbate an over anxious patient. It is feared that doctors

[233] Gilhooley and McGhee (1991).

[234] Information Policy Unit (2004). The National Patient Safety Agency Plan 2003–4 found 1,742 incidents where patients had suffered as a result of bad medical records.

[235] BMA (2004: 199).

[236] BMA (2004: 218). No doubt there are worse things written on medical records.

[237] Ross (1986).

may then have to become involved in lengthy discussions explaining the records to their patient. It may, of course, be regarded as a good thing that doctors explain to patients the details of their medical conditions.

REALITY CHECK

Medical Acronyms

It should not be thought that medical records will only contain medical records. A BBC Newsonline (2003c) report found the following acronyms used in people's records:

CTD—Circling the Drain (A patient expected to die soon)
GLM—Good looking Mum
GPO—Good for Parts Only
TEETH—Tried Everything Else, Try Homeopathy
UBI—Unexplained Beer Injury
NFN—Normal for Norfolk
FLK—Funny looking kid
GROLIES—Guardian Reader Of Low Intelligence in Ethnic Skirt
TTFO—roughly translated as 'Told To Go Away'
LOBNH—(Lights On But Nobody Home)
'Pumpkin Positive'—which refers to the implication that a penlight shone into the patient's mouth would encounter a brain so small that the whole head would light up.

7 The ethical issues

We have so far concentrated on the legal position. The is generally based on the assumption that medical professionals should not breach confidence. But what are the ethical arguments that might support such an assumption?

7.1 Arguments in favour of confidentiality

7.1.1 *Consequentialist arguments*

These arguments rely on the benefits and disadvantages that flow from confidentiality. It is argued that by promising confidentiality patients will be willing to be completely honest with their doctors and discuss all their symptoms and past history.[238] This will mean that the best diagnosis and treatment can be offered. This will benefit both patients and the general public. It will also ensure that there is an efficient and organized health system. Murphy has argued in favour of confidentiality because it encourage 'talk' between the patient and medical professional. In other words it encourages a model

[238] There are psychological studies which support the argument that guaranteeing confidentiality will lead to greater honesty and openness: Knowles and McMahan (1995); Woods and McNamara (1980).

whereby the doctor and patient discuss and agree on an appropriate course of treatment, rather than the doctor providing a monologue setting out the problem and proposed solution, which the patient must simply accept or reject. All of these argument in this paragraph assume that patients are aware of the obligations of confidences under which medical professionals operate and rely on them. Whether this is true is a matter of debate.

7.1.2 *Deontological arguments*

Confidentiality is a fundamental principle should be respected. It has been argued 'The right to control who knows the things about us which we regard as private is integral to our sense of self and sense of identity.'[239] Others ground the right in terms of the right to autonomy: that people should have the ability to live their lives as they choose. This is possible only if private matters being kept secret by those to whom they are divulged. Capron argues that a breach of confidence involves a lack of respect for reserve and solitude.[240] Others emphasize not privacy, but fidelity. In other words a breach of confidence is quite simply a breach of a promise.[241] The obligation of confidence can also be seen a reflection of the fact that patients must submit themselves and their futures to the professional.[242]

7.1.3 *Public/private benefits*

As can be seen from the points above some arguments in favour of confidentiality are in terms of the public good: it aids an effective health care system. When confidentiality is broken not only does that harm the individual concerned it has an impact on the general public's willingness to trust medical professionals and this can harm the health of the nation.[243] Other arguments focus more on the 'private' issues: the rights and harms of the particular individual concerned.

It is of course quite possible to claim that there are both public and private claims that can be made in favour of confidentiality and it would be wrong to emphasize one more than the other.[244] In other words when a doctor breaks a duty of confidentiality not only is there a wrong done to the individual patient, but there is a public harm because patients generally lose trust in the medical profession. Until recently the case law on the equitable protection of confidential information emphasized the public interest in protecting confidential information, as more important than the private interest in maintaining confidence.[245] However it may be that the understanding on the basis of confidentiality has shifted after the Human Rights Act 1998. Indeed the House of Lords in *Campbell v MGN*[246] held that privacy, dignity and autonomy provided the basis of

[239] O'Brien and Chantler (2003).

[240] Capron (1991).

[241] Childress and Beauchamp (2001: 307–10).

[242] Sokolowski (1991).

[243] Hall (2002) emphasizes the importance of trust in good medical practice.

[244] Childress and Beauchamp (2001: 307–10).

[245] *W v Egdell* [1990] 1 All ER 836, *X v Y* [1988] 2 All ER 649.

[246] [2004] UKHL 22.

medical confidentiality. It is arguable that the recognition of the right as a private right will make it more difficult to justify a disclosure on the basic of the public interest.[247] If confidentiality is seen as being in the public interest it is easier to justify an infringement by reference to other public interest claims than it would be if the claim was seen as being a private individual's right.[248] Also if put in terms of the public benefit there are concerns that some groups of people could claim to have a stronger claim than others.[249] It could, for example, be argued it is more in the national interest that medical records of top politicians be kept confidential, than of benefit claimants.[250]

7.2 Arguments against confidentiality

There are very few people who actually believe that confidentiality does not deserve protection at all. But there is a considerable body of opinion who believe that far too much respect is paid to the notion of confidentiality. Paterson argued that the emphasis on confidentiality was an interference with research:[251] Indeed the impact on research has led some to claim that 'privacy is bad for your health.'[252]

Professor Gostin has put the problem well:

> Because significant levels of privacy cannot realistically be achieved within the health information infrastructure currently envisaged by policymakers, we confront a hard choice: should we sharply limit the systematic collection of identifiable health care data in order to achieve reasonable levels of informational privacy? The result of that choice would be to reduce considerably the social good that would be achieved from the thoughtful use of health data. Alternatively, we may decide that the value of information collection is so important to the achievement of societal aspirations for health that the law ought not promise absolute or even significant levels of privacy at all, but rather should require that the data be used only for authorized and limited purposes.[253]

He argues that in a modern health care system the notion of confidentiality between patient and doctor is outdated. We have instead to focus on protection of records and ensuring that that any medical data (however acquired) is used for proper purposes.

Rubinstein[254] makes the point emphasizing confidentiality too strongly carries risks:

> Inherent in the privacy advocates' rejection of the public duty paradigm is a refusal to recognize, in exchange for the vast improvements in medical care, a correlative responsibility on the part of the individual, as a potential consumer of health care services,

[247] Lee (1994: 291).

[248] Lee (1994: 292).

[249] Murphy (1998).

[250] Roberts (1996) is concerned how easily the medical confidentiality of benefit claimants is infringed in America.

[251] Al-Shahi, R. and Warlow, C. (2000).

[252] O'Grady and Nolan (2004).

[253] Gostin (1995: 454).

[254] Rubinstein (1999: 227).

toward the community. As individuals rely on their right to be let alone, they shift the burden on others in the community to accept the responsibility for providing the data needed to advance medical and health policy information. Their individualist vision threatens the entire community, because when particular segments of the community opt out of participation as data subjects, the resulting value of the research is questionable, and many worthwhile protocols could be abandoned on that basis. Thus, a policy that requires consent before each use of health data might have unintended and undesirable consequences for our medical care and health policy.

7.3 Public views

Surveys among the general public in relation to confidentiality might make depressing reading for those who are concerned about the present protection of confidential information. First, the surveys suggest the public has high confidence in the way the NHS protects confidentiality.[255] Second, the surveys suggest that people are not particularly concerned about the fact a large number of people within the NHS may need access to their data.[256] Although there is much unease about information being given to people outside the NHS.[257]

However, the picture is more complicated than this. Although the public are pleased with the way their medical records are kept secret, in fact the general public have little idea how the information is in fact used.[258] For example only 16 per cent of those questioned in one large survey realized that their information could be revealed to hospital managers. Further surveys indicate that when the public are asked if they happy for their medical details to be used in 'medical research' there is much unease. Although they tend to be much happier when asked if they would be willing for their records to be used in a particular project (e.g. to research the causes of cancer).[259] A team researching asthma and angina who decided to write to individuals asking consent to use their medical records found that 9.8 per cent refused. This indicates that that an assumption that nearly everyone wants to help in medical research is ill founded, even when the research might be regarded as uncontroversial.[260]

Surveys do give us some picture of what kind of medical issues people are particularly sensitive about. Not surprisingly they are termination of pregnancy and mental health issues.[261] This might support an argument that medical records should be divided up into general records, readily available for anyone in the NHS with a legitimate reason for seeing it, and a sensitive part which could only be examined on a 'need to know' basis.

[255] National Health Service Information Authority (2002).

[256] Adams, Budden, Hoare and Sanderson (2004).

[257] NHS Information Authority (2002) and Van de Creek, Miars and Herzog (1987).

[258] National Health Service Information Authority (2002).

[259] The Welcome Trust and Medical Research Council (2001).

[260] Baker, Shields, Stevenson, Fraser and Stone (2000).

[261] National Health Service Information Authority (2002).

One study looked at this option and found much support among the general public, but 60 per cent said they would want to be put in the sensitive part.[262]

8 Informational privacy

Laurie[263] has argued that the law should move away from focussing on the notion of confidentiality and instead focus on the right to informational privacy.[264] He explains the difference between the two concepts in this way:

> Informational privacy is concerned with the control of personal information and with preventing access to that information by others. An invasion of informational privacy occurs when any unauthorized disclosure of information takes place. Confidentiality is a subset of this privacy interest is breached when confidential information which is the subject of the relationship is released to parties outside the relationship without authorization. Informational privacy is wider than this in that it requires no relationship to exist[265]

Laurie sees privacy as creating and respecting a 'state of separateness' for individuals; 'the protection of a private sphere around oneself'.[266] It is important for people living in society to have their 'own space'. This may involve a physical space, but also a psychological one. This is only possible if people are able to control who has access to information about them and what information they find out about themselves. Laurie is aware this might sound as if he is advocating a highly individualist vision of society which pays no attention to relationships between people. However, he says that the protection of privacy is important to enable relationships to flourish.[267]

So what exactly is the difference between confidentiality and informational privacy. The differences appear to include the following:

(i) The classic definition of confidentiality requires there to be a confidential relationship between the parties. It therefore does not readily apply where a party acquires private information about another outside the context of such a relationship. There are no such difficulties for the notion of informational privacy which does not depend on any kind of relationship.[268]

(ii) The idea that a party has a right not to know a piece of information can be readily included within the notion of informational privacy. It cannot easily fit into the notion of breach of confidence.

[262] National Health Service Information Authority (2002).

[263] Laurie (2000: chapter 7).

[264] For further discussion on the nature of privacy see Neill (1999).

[265] Mason, McCall Smith, and Laurie (2001: 212).

[266] Laurie (2004: 128).

[267] See Andorno (2004) who develops the right not to know from autonomy rather than privacy.

[268] Mikolowski (2004: 16–18).

(iii) Laurie suggests that an understanding of a right to information privacy when combined with a proprietal right over medical information about a person will give a person appropriate control over their medical details. In particular it will mean that a person can have on-going control over how their records are used. He is concerned that with breach of confidence once consent is given for the public use of the information then the protection is lost.

A SHOCK TO THE SYSTEM

The following shows that it is possible to respect confidentiality too much.

In January 1999 Maine in the USA enacted a strict law prohibiting medical information without a patient's written consent (see C. Scott (2000)). Heavy fines would be placed on those who violated the rules. The law was soon found to be impracticable: relatives of patients who telephoned for updates could not be told; florists found it impossible to deliver flowers; priests could not discover the whereabouts for patients to administer religious rites; doctors found it difficult to consult over problems with patients; delays occurred because labs refused to give the results of tests over the telephone.

There is also some evidence that following the Data Protection Act 1998 some health care trusts became so nervous of infringing that Act that they refused to provide information to outside bodies, even where to do so would be uncontroversial (Boyd 2003).

9 Conclusion

A survey of patients across European countries found that they regarded confidentiality as 'very important' and one of their highest priorities when consulting doctors.[269] And, if the professional guidelines are anything to go by, health care workers take the duty of confidentiality seriously. Yet there is little doubt that medical confidentiality is under threat. In practice the flimsy curtain in hospitals with medical notes at the end of a bed mean that in that setting confidentiality is little protected.[270] The desire to ensure the National Health Service is run effectively and efficiently mean that managers and administrators need to have access to records to an extent never needed before. Further inevitably computerization of health records will increase and with that the difficulties of ensuring that the information is kept secure.[271] Insurance companies seek ever more intimate medical information about people seeking life insurance.[272] It is not surprising that some commentators have described confidentiality as a 'decrepit concept'.[273]

[269] Grol et al (1999).

[270] Okino Sawada et al (1996).

[271] Gostin, Hodge and Burghard (2002).

[272] Royal College of General Practitioners (2000) are concerned about this.

[273] Siegler (1982).

The ambiguity over the notion of confidentiality is also found in the shift of language in some court cases[274] and professional guidance[275] from talk of a duty of confidentiality to a discussion of the fairness of use of information. Maybe this is realistic: the NHS cannot promise that your information will not be disclosed to anyone else, but it can promise that your information will be dealt with fairly. But there are influences the other way. The Human Rights Act 1998 appears to classify protection of private information as a human right.[276] Especially in the area of genetic information there is widespread unease about the way such information is used. Also there is increasing concern at the lack of trust between patients and doctors which is central to an effective health care system. A reaffirmation of the importance confidentiality could be seen as one way of restoring that trust.[277]

QUESTIONS

1. Proposals to take DNA profiles of every baby born in the UK have been rejected by the Human Genetic Commission (BBC Newsonline (31 March 2005)). What ethical issues would be raised by such a database?
2. There are plans for all medical records within the NHS to be computerized. Is this a concern? How should the balance be struck between the importance of keeping information confidential and ensuring that medical professionals have ready access to the medical information necessary to treat a patient?
3. Should the law do more to distinguish between different kinds of medical information? It might, for example, be argued that we could distinguish non-intimate medical information (e.g. the fact a person has broken a leg) from intimate information (e.g. the fact a person has had an abortion). Would that be a useful distinction?
4. Can you think of any medical information about yourself that you would rather not know? How can the law respect that wish?
5. Does it matter whether the protection of medical confidential information is regarded as a matter of private rights or public interest or both?

FURTHER READING

Generally on the protection of confidential medical information see: Andorno (2004); Gilbar (2004); Gurry (1985); Laurie (2002); Mikolowski (2004); Moreham (2005); Pattenden (2003); Skene (2001).

On the protection of genetic information see: Canadian Biotechnology Advisory Committee (2004); Laurie (2003).

On HIV issues see: Bennett and Erin (2001).

[274] *Department of Health ex p Source Informatics Ltd* [2000] 1 All ER 786.
[275] NHS (2003: 1).
[276] Evans and Harris (2004) are concerned at the shift away from protecting confidentiality as a right.
[277] Clarke (2002).