

# Introduction

Confidentiality is seen as a fundamental ethical principle in health care and a breach of confidentiality can be a reason for disciplinary action. Dilemmas around confidentiality arise when the principle of confidentiality is in possible conflict with other ethical principles such as avoiding harm to the patient or others. Issues around confidentiality may be brought to a clinical ethics committee or group in the form of individual cases or in considering hospital policies. There are also issues of confidentiality for the ethics committee itself. In this section we provide a brief overview of the ethical and legal approaches to confidentiality and then look at some specific issues that may present to ethics committees. We describe a hypothetical case to illustrate the issues that might be brought to a committee by health professionals, and then look at the duties of the committee regarding confidentiality and access to records in health care. The section concludes with some suggested further reading on the issues.

This section does not provide a comprehensive overview of the issues around confidentiality, and does not make recommendations about what an ethics committee should do. It highlights issues that a committee may wish to consider and provides some ethical and legal frameworks for approaching the subject.

## Ethical Considerations

Confidentiality can be considered from a number of different ethical perspectives.

### Respect for patient autonomy (deontological theory)

The principle of respect for patient autonomy acknowledges the right of a patient to have control over his or her own life – and this would include the right to decide who should have access to his/her personal information. Can there be a breach of confidentiality if a patient never knows that the healthcare professional has disclosed the information? Where the basis for the duty of confidentiality is the principle of respect for autonomy **any** breach of confidentiality means that the patient's autonomy has not been respected, whether or not the patient is aware of the breach.

### Implied promise

The health professional-patient relationship could be seen as having elements of an implied contract and this could include an implied promise that health professionals keep information about their patients confidential. It is reasonable for patients to expect that information they divulge to their doctors or other health professionals will be kept confidential. If confidentiality is subsequently breached the patient may feel that a promise has been broken. This view of confidentiality is different from that of patient autonomy because it depends on the concept of the doctor-patient relationship rather than what the patient wants or believes.

### Virtue Ethics

Virtue ethics focuses on the position of the doctor rather than that of the patient (as is the case with respect for autonomy). This approach asks what a virtuous doctor would do in the particular circumstances - what issues would a virtuous doctor take into account in deciding whether or not to disclose confidential information?

## Consequentialism

From a consequentialist position the question of whether it is wrong to breach confidentiality is determined by the consequences of the breach. One of the consequences of a breach of confidentiality could be that the patient will lose trust in his/her doctor, and perhaps doctors generally, resulting in him/her not accessing healthcare in the future with a detrimental effect on his/her (and others?) health. On the other hand there may be situations where there are bad consequences of **not** breaching confidentiality, for example third parties may be denied information which would have serious implications for their health and treatment.

## Professional Guidelines

The General Medical Council (GMC) has published guidance on confidentiality, including general guidance and guidance in specific situations. . *(Although they do not have the force of law, the courts do consider such guidance to have persuasive authority).*

Confidentiality: Protecting and Providing Information, 2004 GMC  
Serious Communicable Diseases 1997

The Nursing and Midwifery Council (NMC) provides for a duty of confidentiality.  
Code of Professional Conduct (2002) clause 5.

Confidentiality: NHS Code of Practice 2003.  
Replaces previous guidance, HSG (96)18/LASSL (96)5 - The Protection and Use of Patient Information.

The new code is a guide to required practice for those who work within or under contract to NHS organisations - it deals with confidentiality and patients' consent to the use of their health records.

The code is a key component of emerging information governance arrangements for the NHS.

The code can be downloaded from <http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>

### **GMC Booklet: Serious Communicable Diseases**

#### Giving Information to Close Contacts

You may disclose information about a patient, whether living or dead, in order to protect a person from risk of death or serious harm. For example, you may disclose information to a known sexual contact of a patient with HIV where you have reason to think that the patient has not informed that person, and cannot be persuaded to do so. In such circumstances you should tell the patient before you make the disclosure, and you must be prepared to justify a decision to disclose information (*paragraph 22*).

You must not disclose information to others, for example relatives, who have not been, and are not, at risk of infection (*paragraph 23*).

### **GMC booklet: Confidentiality Protecting and Providing Information**

Disclosure of personal information without consent may be justified where failure to do so may expose the patient or others to risk of death or serious harm. Where third parties are exposed to a risk so serious that it outweighs the patient's privacy interest, you should seek consent to disclosure where practicable. If it is not practicable, you should disclose information promptly to an appropriate person or authority. You should generally inform the patient before disclosing the information (*paragraph 36*).

**Disclosure can therefore only be justified where an identifiable person is at serious risk.**

## Legal Considerations

There is a public interest in health professionals maintaining patient confidentiality - this encourages patients to fully divulge relevant information so that the healthcare professional can make a proper assessment of the patient's condition. On the other hand there may, occasionally, be circumstances where the interest in maintaining confidentiality is outweighed in the public interest (disclosure to prevent a crime, for the health interests of others etc) and this justifies disclosure of confidential patient information without consent. The health professional will have to balance these competing public interests in deciding whether or not to disclose. Assistance can be gleaned from legal cases and professional guidance (the courts do take account of these).

### **W v Edgell [1990] 1 ALL ER 835**

The patient was a prisoner in a secure hospital following convictions for killing five people and wounding several others. He made an application to a mental health tribunal to be transferred to a regional unit. An independent psychiatrist, Dr Edgell, was asked by W's legal advisors to provide a confidential expert opinion that they hoped would show that W was no longer a danger to the public. However Dr Edgell was of the opinion that in fact W was still dangerous. W's application was withdrawn. Dr Edgell, knowing that his opinion would not be included in the patient's notes, sent a copy to the medical director of the hospital and to the Home Office.

The patient brought an action for breach of confidence.

The Court of Appeal held that the breach was justified in the public interest, on grounds of protection of the public from dangerous criminal acts. However, the Court said the risk must be 'real, immediate and serious'.

### **X v Y [1988] 2 ALL ER 648**

A Health Authority sought an injunction to prevent a national newspaper publishing the names of two practising doctors who were receiving treatment for AIDS. The Court balanced the public interest in freedom of the press against the public interest in maintaining hospital records confidential. The Court found that lack of publication of the information would be of minimal significance since there was a wide ranging public debate about AIDS generally.

In balancing these competing interests it should be noted that disclosure should in any event only be made to a relevant party - there should be no blanket disclosure.

See also: **H (a Healthworker) v Associated Newspapers Ltd [2002]**

**EWCA civ 195. Times, March 19, 2002** in which again the Court of Appeal reiterated the strong public interest in maintaining the confidentiality of health workers infected with HIV.

## Statutes requiring disclosure

Some statutes require disclosure of confidential information where this would otherwise be a breach of confidentiality. These include:

### *Police and Criminal Evidence Act 1984*

The police can **access** medical records for the purpose of a criminal investigation by making an application to a circuit judge.

### *Public Health (Control of Disease) Act 1984 and Public Health (Infectious Diseases) Regulations 1988*

A doctor must notify the relevant local authority officer (usually a public health consultant) if he suspects a patient of having a notifiable disease. AIDS and HIV are not notifiable diseases.

### *Abortion Regulations 1991*

A doctor carrying out a termination of pregnancy must notify the relevant Chief Medical Officer including giving the name and address of the woman concerned.

### *Births and Deaths Registration Act 1953*

The doctor or midwife normally has a duty to inform the district medical officer of a birth within six hours. Stillbirths (a baby born dead after 24th week of pregnancy) must be registered. Doctors attending patients during their last illness must sign a death certificate, giving cause of death.

### *Road Traffic Act 1988*

All citizens, including doctors, must provide the police, on request, with information (name, address), which might identify a driver alleged to have committed a traffic offence. This would not normally justify providing clinical information without the patient's consent, or a court order. A doctor may have a legal obligation to inform the DVLA if he has concerns that a patient has a medical disability that could affect his driving.

### *Human Fertilisation and Embryology Act 1990*

The Human Fertilisation and Embryology Authority maintains a register of individuals receiving fertility treatment.

### *NHS (Venereal Diseases) Regulations 1974*

Allows limited disclosure of information for contact-tracing in the case of sexually transmitted diseases. Such disclosure can only be made to a doctor, or to someone working on a doctor's instruction in connection with treatment or prevention. It forbids those working in a genito-urinary clinic to inform an insurance company of a patient's sexually transmitted disease – even with the patient's consent. GP's are not routinely informed of the patient's attendance at such clinics, although the patient may request that the GP be informed.

### *Children Act 1989*

Regulates many aspects of childcare including professionals' duties when there is suspicion of child abuse.

### *Human Organ Transplants Act 1989*

Doctors who either remove certain organs (kidney, heart, lung, pancreas, liver) for transplant, or who implant such donated organs must report the names and hospital numbers of donor and recipient to the UK Transplant Support Service Authority and the relevant health authority.

### *Prevention of Terrorism (Temporary Provisions) Act 2000*

All citizens, including doctors, must inform police, as soon as possible, of any information that may help to prevent an act of terrorism, or help in apprehending or prosecuting a terrorist.

## **Case Study**

**The following is a worked example of a hypothetical case study showing how ethical principles would apply to a practical problem.**

Bob has attended the genito-urinary clinic at his local Trust hospital. Bob is seen by Dr Gomez who informs him that he is HIV positive. Dr Gomez counsels Bob to contact his sexual partners to inform them of his status. Bob starts a course of treatment.

For the last 18 months Bob has been in a relationship with Sue. They are expecting a baby in 2 months time. Before this relationship Bob had a series of sexual partners.

On a subsequent visit to the clinic it becomes clear to Dr Gomez that Bob has not told Sue of his HIV status. Dr Gomez is aware of the impending arrival of their baby and tells Bob that steps should be taken to assess whether Sue is HIV positive and whether the baby is at risk so that if necessary treatment may be started.

Bob adamantly refuses to tell Sue and says that if she is told without his consent then he will stop his course of treatment.

What should Dr Gomez do? Can / should he inform Sue, or Bob's GP?

### **Issues to consider**

The principle of respect for autonomy requires that personal information should not be disclosed without consent. However, in some cases the autonomy of another person may also be at issue (in this case Sue and previous sexual partners, as well as the baby when born). Not disclosing information may limit their ability to make decisions as to treatment and lifestyle.

Although maintaining confidence in personal information may be the starting point, a balance of the benefits and harms of disclosure / non-disclosure leads to consideration of the consequences of a course of action.

In this scenario the harms of non-disclosure can be identified as:

- The risk that Sue may be HIV positive. The consequence of not providing information to enable her to be tested is that she is harmed by not knowing her HIV status and not receiving a course of treatment.
- If Sue is HIV positive and is not aware of the risk the consequences are that she will not take steps to minimise the risk of infection to the baby eg. obtaining treatment during pregnancy, baby born by caesarean section, knowing not to breastfeed, prophylactic treatment.
- If Sue did later find out that there was a risk to her and that she was not informed she

- may lose trust in her doctor or the healthcare system.
- Risks to Bob's former identifiable sexual partners who could be contacted and informed.

The harms of disclosure would include:

- If the clinician informs others without Bob's consent then as a consequence he may lose trust in Dr Gomez, and perhaps the medical profession in general.
- He has indicated that he will end his course of treatment thus risking relapse and severe health problems including death.
- There is also a risk that he could go on to infect future sexual partners.
- Bob may be stigmatized by others who get to know and may have problems with future employment because of discrimination

## **Applying ethics and law - balancing competing interests and values**

It is necessary to balance the potential harms of non-disclosure with the harms that might result from disclosure without consent in breach of the duty of confidentiality.

Paragraph 22 of the GMC guidance - Serious Communicable Diseases (see above) allows disclosure to a known sexual contact where the patient has not informed that person and cannot be persuaded to do so. As Sue is an identifiable individual at serious risk disclosure to her would be justified (is she living at the same address? - if not and she could not be traced then if Bob and Sue share the same GP the GP could be informed in order to tell Sue). Bob should be informed of the decision to disclose to Sue.

Paragraph 22 refers to 'known sexual contacts' so it is necessary to rely on Bob providing information in order to contact previous sexual partners. It is more practically difficult to avert harm - can previous partners be contacted directly? If not can contact be made through their GPs? It may be more difficult to justify disclosure to previous sexual partners because the net of disclosure has spread far wider and the benefits of disclosure are less easily identifiable. A very difficult balancing of interest, harms and benefits based on the facts would need to take place to consider whether disclosure is justified.

**A useful comparison could be made with disclosure of genetic information.** Genetic information may have great relevance for the health of relatives. Nevertheless, if the patient refuses to allow relatives to be informed confidence should be maintained unless the health interests' of family members' to be given such information outweighs the duty of confidentiality.

BMA guidance (Human genetics: choice and responsibility 1998) states that a healthcare professional should consider the following factors in deciding whether to disclose:

- Severity of the disorder
- Level of predictability
- Action relatives could take
- Harms / benefits in giving or withholding information

What about the interests of the child to be born? In **Re C (HIV testing) [1999] 2 FLR 1004** the court considered that it was in the best interests of a baby to undergo testing for HIV (where the mother was HIV positive and had refused interventions to prevent transmission of the virus) despite the fact that the parents refused their consent. Clinicians were of the view that if the child was infected measures could be taken to manage the condition. The court said that the child had interests that were separate from those of its parents (a foetus does not have legal rights but rights do crystallize at birth).

In the case study scenario it would be necessary to consider the likelihood of HIV risk to the baby to determine whether breach of confidentiality is justified. Sue would need to be informed in order to consent to testing / treatment.

Should Bob's GP be informed? Paragraphs 18 and 19 of GMC, Serious Communicable Diseases states that "you should make sure the patient (Bob) understands that general practitioners cannot provide adequate clinical management without knowledge of their patient's conditions". If Bob still refuses his wishes must be respected unless failure to disclose would put a health care worker or other patient at serious risk of death or serious harm.

This section relates to disclosure to health professionals because of risk to them or inadvertent risk to their other patients. It is separate from disclosure to those directly at risk such as Sue.

It would appear, in balancing the harm to Bob with harms to others that the harm to Bob in disclosing without his consent is outweighed by the harmful consequences of not disclosing. However health professionals working in this area may consider that more weight should be given to the loss of trust that might result from breaching confidences.

Compelling ethical reasons exist for protecting the privacy of persons with HIV infection. An important justification for privacy resides in the principle of respect for autonomy. To respect the privacy of persons with HIV/AIDS is to respect their wishes not be observed or to have intimate information about themselves made available to others. Privacy also enhances the development of trust in the physician. One of the defining characteristics of the doctor/patient relationship involves the sharing - freely given - of private information. Failure to respect the confidentiality of patients drives patients away from HIV testing, counseling, and treatment, and discourages patients from confiding in their physicians. Healthcare facilities that treat persons with HIV argue fiercely that compelling physicians to disclose HIV infection to sexual or needle-sharing partners would mean they would lose the trust of their clients.

Lawrence O. Gostin, JD, from the September, 1995 issue of the *JIA PAC*.

## **Clinical Ethics Committees and the Duty of Confidentiality**

### **Sharing information within teams**

- In what circumstances can information be shared within a healthcare team?
- Is a Clinical Ethics Committee part of a 'team' for this purpose?
- To what extent should Clinical Ethics Committees discuss an individual case without telling the patient concerned?

### ***GMC guidelines; Confidentiality; Protecting and Providing Information*** **Disclosure of information necessary for treatment**

"Where patients have consented to treatment, express consent is not usually needed before relevant personal information is shared to enable treatment to be provided (*paragraph 7*)

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 the reasons for this (*paragraph 8*)

Anyone to whom personal information is disclosed in confidence must respect the confidence (*paragraph 9*)

*A Clinical Ethics Committee would not be considered part of a treating team so the GMC guidance above would suggest that consent may be needed if identifiable information is to be shared with an ethics committee. The guidance states that patients should be aware that personal information could be shared to enable treatment to be provided. An ethics case consultation may fall into this situation, suggesting that patients should be informed.*

### **Disclosure unlikely to have personal consequences for patients**

Disclosure for use in education or training, clinical or medical audit is unlikely to have personal consequences for the patient. In these circumstances you should still obtain patients' express consent to the use of identifiable data or arrange for members of the healthcare team to anonymise records (*paragraph 15*).

Anonymised data is defined as data from which the patient cannot be identified by the recipient of the information. NHS numbers may be included only if recipients of the data cannot trace the identity of the patient.

*The use of retrospective cases for education of the ethics committee, or for learning for future cases, could be seen as falling into this category. Therefore, provided the patient cannot be identified from the information, express consent may not be needed. However the question of how anonymou*

## **Clinical Ethics Committees and Access to Health Records**

Patients, or their relatives, may want access to the written record of the deliberations of the committee, assuming that they have been informed.

- What is the responsibility of a Clinical Ethics Committee to provide access to minutes of a committee meeting?

### **Data Protection Act 1998**

The subject access provisions of the Data Protection Act 1998 provide that an individual having submitted a request in writing is entitled to be provided with a copy of the personal data held about him or her. "Personal data" is defined as information that relates to a living individual who can be identified from the data. This would therefore include health records and possibly minutes of Clinical Ethics Committee meetings.

Information need not be disclosed however, where another individual can be identified from that information (except where that individual is a health professional who has contributed to the care and treatment of the patient). This data should be withheld unless the other individual has consented to the disclosure.

Where the treatment and care of a patient has been subject to discussion by a clinical ethics committee the patient could have access to notes / minutes of the meeting if he /she could be identified from them. However access may be denied if individual members of the committee who are not healthcare professionals (legal, lay, religious members) could be themselves identified from the minutes (and they do not consent to such disclosure). It is therefore relevant whether the minutes identify comments from individual members of the committee or give an opinion of the committee as a whole.

## **Freedom of Information Act 2000**

The Freedom of Information Act gives a general right of access to all types of recorded information held by public authorities (NHS bodies are public authorities). The right of access to information under this Act does not come into force until the 1st January 2005.

Any person who makes a request to a public authority for information will have to be told whether information is held and that information must be supplied. However there are a number of exemptions.

Public Authorities are also required to proactively make some of the information they hold available through a publication scheme. The publication scheme must organise the information to be published into classes and then set out how that information is to be published. Model publication schemes have been approved for various health sector bodies.

The Network is considering the applicability of the provisions of the Act to minutes of Clinical Ethics Committees.

## **Caldicott guardians**

In 1997 the Department of Health published the Caldicott Report ('On the Review of Patient-Identifiable Information'). It considered the flow of identifiable patient information and recommended that confidentiality should be safeguarded by anonymising health data, where possible. Each NHS organisation must have a 'guardian' (normally a senior health professional) to oversee all procedures affecting access to person-identifiable information.

[www.doh.gov.uk/ipu/confiden/report/index.htm](http://www.doh.gov.uk/ipu/confiden/report/index.htm)

## **Reading**

Beauchamp and Childress, Principles of Biomedical Ethics, Fifth Edition, Oxford University Press 2001, p 303

Hope, Savulescu and Hendrick, Medical Ethics and Law, the core curriculum, Churchill Livingstone 2003, chapter 7

### **Symposium on Consent and Confidentiality.**

Consent and confidentiality – where are the limits? An introduction, P J Lachmann. J Med Ethics 2003; **29**: 2

Consent and confidentiality in genetics: whose information is it anyway?, A. Kent. J Med Ethics 2003; **29**: 16 – 18

The requirements of the Data Protection Act 1998 for the processing of medical data. P. Boyd. J Med Ethics 2003; **29**: 34-35

Confidentiality and the duties of care. J O'Brien, C Chantler, J Med Ethics 2003; **29**: 36-40

Patient privacy and confidentiality, Jim Chalmers and Rod Muir, BMJ 2003; **326**: 725-726.

Confidentiality and cognitive impairment : professional and philosophical ethics. JC Hughes and SJ Louw. Age and Ageing, 2002; **31 (2)**: 147 - 150

The criminalisation of HIV transmission. J Chalmers J Med Ethics 2002; **28**: 160 - 163

Wife wins case against GPs who did not disclose husband's HIV status, Christopher Zinn, BMJ; **326**: 1286

Sharing patient information electronically throughout the NHS, Nick Booth, BMJ 2003; **327**: 114-115

New consent form designed for release of medical records, Clare Dyer, BMJ 2003; **327**: 122

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