

Confidentiality and disclosure of health information

Guidance from the BMA's Medical Ethics Department



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Foreword

Questions about confidentiality and disclosure are a staple area of ethical enquiry for the British Medical Association (BMA). The volume of such queries outstrips other issues of ethical concern raised by BMA members. While doctors are aware of their traditional obligations to protect confidentiality, they also recognise that ever more complex dilemmas arise from that duty. This guidance addresses some of the frequent questions put to the BMA.

General guidance cannot provide definitive answers for every situation. Much depends on the context of the individual case. Our aim, therefore, is to explore the key factors which need to be taken into account when such decisions are made. Ultimately, doctors must make a reasoned analysis of the best course of action in a particular case. Normally, they do this together with patients. In some cases, however, this is impossible because patients are unconscious or lack mental capacity. Some lack insight into how their wishes badly infringe the rights of other people to have information that would help them protect their own health. The most difficult dilemmas of all often arise in cases of possible child abuse or other criminal activity where individuals refuse to allow disclosure of information, despite the fact that silence puts other people at risk of harm.

Interpretations of law and ethics are subject to change. Like any other advice, this document will need to be periodically updated. Rarely is there an ideal time to issue guidance as there is always some potential change in sight and doctors need to know that some issues in this document may develop in the foreseeable future. Aspects of the implementation of the Human Rights Act, for example, may impact on future perceptions of personal privacy. As a result of a challenge in the European Court of Human Rights in 1999, new guidance may emerge for armed forces' doctors in respect of the duty to report homosexuality. Debate about acceptable uses of anonymised data may be taken forward later in 1999, as is indicated in the text. In any case of doubt, doctors should check the BMA's ethics website for the latest guidance or contact the Ethics Department or the General Medical Council.

In addition to specific areas where some change may be expected, queries around confidentiality and disclosure are generally becoming more complicated. Developments in genetic testing mean that GPs increasingly hold genetic data that arguably "belongs" in some sense to all of the family rather than just one individual. Confidentiality after the patient's death can be complicated by relatives' wishes and their rights under the access to health records legislation. Medical information is regularly requested by third parties for a range of social purposes, such as patients' eligibility for state benefits, employment or insurance. Parallel with this, a growing recognition of children's autonomy means that disclosure of a young person's medical data, even to parents or social workers, can involve complex considerations. Particularly frequent areas of concern are questions around disclosure in cases where some aspect of patients' health may seriously harm others, such as by sharing contaminated needles or through driving with seriously impaired eyesight. The rights of family members to privacy can also come into conflict

with the public interest when health records indicate suspicions of non-accidental injury to a vulnerable child or adult. There is an ever growing list of demands on doctors to disclose information to third parties such as insurers, the police, social workers or driver licensing authorities. Over time, the BMA has developed a body of advice on such issues which is summarised in this document.

It is also worth noting that the BMA has also made unsuccessful efforts to clarify aspects of the law in respect of confidentiality. Two successive working parties looked at the issues. The Inter-Professional Working Group, initially established by the Department of Health, met regularly at the BMA over the latter part of the 1980s. It produced a draft Parliamentary Bill and accompanying handbook on medical confidentiality and disclosure. The BMA's annual representative meeting in 1994 called for publication of such a code but legal ownership of the copyright of these multi-professional deliberations remained unclear, with the result that they were not widely published. Nevertheless, as uncertainty about ethical and legal aspects of confidentiality continued in response to changes such as new billing and purchasing arrangements in the health service, the work was picked up in 1994 by a second working party. Under the chairmanship of Geoffrey Robertson QC, a wide range of health organisations participated and representatives of social workers and patient interests were consulted. In July 1994, the BMA issued a press release about the continuing need for confidentiality legislation and published an updated Bill and handbook. Although introduced into the House of Lords by Lord Walton, the *Collection, Use and Disclosure of Personal Health Information Bill* was, unfortunately, never picked up by the government. Nevertheless, the BMA remains interested in exploring how aspects of confidentiality and disclosure could be clearly defined in law.

Part of the rationale for demanding statute was to extend to all others employed in the provision of health care - both in the private and state sector - the same sort of restraints on disclosure by which doctors and nurses are bound through their professional codes. Managers and administrators may have quite different perceptions about confidentiality to those of patients and health professionals. This needs to be addressed. Similarly, patients may not be fully aware how use of their anonymised health data could help in areas such as medical research which benefits everyone. We have principally sought to address the dilemmas raised by doctors but recognise that this needs to be supplemented by clear advice and information for others with a strong interest in these issues. The BMA would, therefore, like to encourage other organisations, including those representing patients, to ensure that more information is generally available about the uses of health data and about the right of confidentiality.

Furthermore, it is well recognised that patient confidentiality is desirable but not an absolute concept and can be breached if circumstances warrant such action. Problematically, however, no detailed or comprehensive analysis of the kind of factors which would warrant such disclosure has been published. Drawing heavily on published advice of professional bodies, particularly that of the General Medical Council, we seek to rectify that omission in the present document.

Dr Michael Wilks
Chairman, BMA Medical Ethics Committee
14 October 1999

Membership of the Medical Ethics Committee

A publication from the BMA's Medical Ethics Committee whose membership for 1998/99 was:

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1 Introduction

1.1 Background

In 1998, a Data Protection Act was given Royal Assent. The legislation followed lengthy consultation and debate, and comes into force on 1 March 2000. The UK Data Protection Registrar identified the need for a thorough review of data protection legislation back in 1996, and at the same time called for the development of codes of practice by trade associations and representative bodies.¹ The BMA had already spent over a decade working with representatives of other health professionals' organisations drawing up a draft Parliamentary Bill and an accompanying handbook or code of practice applicable to all health professionals.² The Bill entitled *Collection, Use and Disclosure of Personal Health Information* was introduced into the House of Lords by Lord Walton in 1996 but did not progress. It aimed to establish a legal framework governing the systematic collection of identifiable health data in any format, its use and release to people other than the patient. The BMA continues to support primary legislation in this area, and urged the Government to take the opportunity of the requirement from Europe to implement the 1995 EC Data Protection Directive³ to bring in comprehensive privacy legislation. But the resulting legislation, whilst going some way to clarifying the responsibilities of those working in private and public health care, does not provide the framework the BMA considers to be necessary.

1.2 Purpose of the guidance

The purpose of this guidance is to set out the Association's views and policy, to draw together guidance from professional and regulatory bodies and, most importantly, to provide advice to doctors on their obligations and responsibilities in relation to the disclosure and use of personal health information. It is addressed primarily to doctors but in most cases the professional and ethical obligations of all health professionals are similar and therefore it may be of assistance to others. Similarly, medical students should be familiar with their ethical responsibilities when coming into contact with patients or confidential information, and this guidance will be of relevance to them.

1.3 Scope of the guidance

This guidance aims to set the scene by outlining responsibilities in relation to confidentiality, and describing why there are limits to confidentiality. The remainder of the guidance describes where these limits lie. It does not include every situation doctors will be faced with, but articulates and sets general principles which must be adhered to. Some situations where additional considerations may apply, or which are common sources of enquiry to the BMA, are addressed specifically.

1.4 Anonymised information

A principle which underpins the BMA's views on confidentiality and access to information is that information may be used more freely if the individual from whom it originated cannot be identified from it. Although safeguards to prevent inappropriate use or abuse should be in place, in general the Association believes that it is not ethically necessary to seek consent to the use of anonymous information.

In the past, discussion about the use of anonymised information has focussed on what can be considered to be truly anonymous. For example, pieces of information such as date of birth, diagnosis or postcode may not alone identify an individual, but may do so in combination. Similarly, an NHS number may replace other identifiers, but the information cannot be said to be anonymous if it would be possible to obtain the patient's identifying details from, for example, a database of NHS numbers. Indeed, it is arguable that information which is about an individual cannot be anonymised and true anonymisation can only arise with aggregation. Where, however, it is possible to separate completely clinical or administrative information from anything which may permit identification of an individual, the BMA's ethical position is that it may be used without patient consent.

Issues around anonymisation have been further complicated by a legal judgment in which Mr Justice Latham concluded that the Department of Health was entitled to advise that anonymisation of information (with or without aggregation) does not remove the duty of confidentiality towards the subjects.⁴ The case was brought by a commercial company which sought to obtain anonymous information from pharmacists and sell it. Uses for other purposes, and non-commercial uses, did not fall to be decided in the case, although the judge commented that he considered that it could be the case that consent can properly be taken to be implied where "doctors and the Health Service itself use anonymous material for the purposes of research, medical advancement or the proper administration of the Service". The judgment will be appealed and updates relevant to this guidance will be available from the BMA's Medical Ethics Department and on the BMA website (www.bma.org.uk).

The BMA has not revised its ethical position, and continues to believe that disclosure of truly anonymous information does not breach confidentiality. Until the legal position is clear, however, doctors are advised to seek legal advice on their responsibilities relating to the disclosure of anonymous information without consent. A discussion of the nature of implied consent is given in section 3.7.

1.5 Further advice

Further advice about the legal and ethical duties of doctors is available in books and guidelines from the Medical Ethics Department of the BMA. Certain specific aspects of confidentiality are addressed in separate guidelines, and these are referenced throughout the text. A bibliography of relevant BMA documents is included at the end of this paper. Individual enquiries from doctors can also be addressed in writing to the Medical Ethics Department of the BMA.

2 The context

2.1 The moral duty of confidentiality

Respect for confidentiality is an essential requirement for the preservation of trust between patients and health professionals. Confidentiality should only be breached in exceptional cases and with appropriate justification. Personal health information is collected to provide care and treatment to individuals and generally must not be used for other purposes without the individual's knowledge and

permission. Similarly refusals to allow health information to be shared should only be overridden where an overwhelming justification can be shown. No problem arises when individuals give properly informed consent to their information being disclosed to a third party. It is therefore important that health professionals ascertain the individual's view when disclosure is likely to be at issue.

Professional obligations to safeguard the privacy of patients are clearly enunciated in ethical codes and health professionals themselves are entitled to the same rights when they are ill. Loyalty to co-workers is also an accepted precept. Professional and regulatory bodies emphasise, however, that health professionals have an obligation to take action when a colleague poses a threat to patients. Rules governing disclosure without consent are essentially the same whether the information relates to a patient or colleague, although the nature of the duty owed to the individual may differ. In either case, it is normally good practice to discuss voluntary disclosure with the individual before disclosing information without his or her consent.

Some situations of uncertainty or potential conflict can be addressed by frankly discussing with the patient the need for, or benefits of, voluntarily sharing information. Even when the individual's agreement is unlikely, the BMA maintains that it is good practice in most circumstances to inform individuals before any disclosure is made, including those in the "public interest" (see section 3.8). Information disclosed without consent should be the minimum necessary to achieve the objective. Health professionals who breach patients' confidentiality without consent must be prepared to justify their actions to their disciplinary bodies. On the other hand, if they fail to take steps to release information which might prevent a foreseeable tragedy, they will also be open to criticism and complaint.

All patient-identifiable health data, whether written, computerised, visually or audio recorded or simply held in the memory of health professionals, is subject to the rules of confidentiality. A doctor has been struck from the medical register, for example, for casually discussing a patient with another health professional although no documentary disclosure took place.⁵ Doctors also have obligations relating to information storage and use, and are held responsible for any breaches of confidentiality resulting from insecure handling.⁶

2.2 The public interest in confidentiality

In addition to the traditional duty of medical secrecy which has been incorporated into the professional codes of health workers, there is also a strong public interest in maintaining confidentiality so that individuals will be encouraged to seek appropriate treatment and share information relevant to it. Part of the BMA's emphasis on confidentiality and young people, for example, is based on the fact that minors are likely to avoid consulting health professionals for contraception, abortion, treatment of sexually transmitted infections or substance abuse where they are not confident of the privacy of the consultation.⁷ Similarly the BMA has opposed proposals that doctors should become involved in reporting suspected illegal immigrants who present for treatment, partly because it believes doctors should not be seen as agents of the state in such matters and also because

of the potential public health consequences of discouraging such patients from seeking medical advice.

2.3 New challenges to confidentiality

The traditional concept of confidentiality is increasingly challenged by developments which can make it more difficult for patients and health professionals to control information linkage and leakage. The advent of new communications technology and the development of genetic testing are just two examples of such challenges. The proliferation of data flows is noted in the Department of Health's 1997 report on the review of patient-identifiable information (The "Caldicott report"), in which each of an identified 86 flows of information were examined.⁸ The report made 16 recommendations about the use of data within the health service, including the appointment of organisational guardians to oversee issues of confidentiality, a programme to increase awareness of confidentiality and information security in the NHS, the introduction of a new NHS number, and standards and protocols against which to judge the justifications for information use. The BMA's views on those standards are reflected in this document. The problems associated with the networking of databases within the health service and the use of identifiable patient data for purposes other than the provision of care have been addressed in detail by the BMA elsewhere.⁹

At the BMA's annual meeting in 1999, the Association's members noted these issues in passing the following resolution:

That this Meeting believes that there should be continued vigilance with respect to patient confidentiality in a time of great technological and organisational change within the NHS.¹⁰

3 Definitions

3.1 Confidentiality

The principle of keeping secure and secret from others, information given by or about an individual in the course of a professional relationship.

Patients have a right to expect that identifiable information about themselves provided or discovered in the course of their health care will not be shared with other people without their knowledge, and the disclosure of identifiable information without subject consent to someone who did not previously know it breaches confidentiality. Nevertheless, recognition of the importance of confidentiality should not impose unnecessary restrictions on what most patients rightly perceive as the essential purpose of providing it: the delivery of appropriate and effective care to themselves. Furthermore, while patients' rights to privacy and control of their data are important they are not absolute. Occasions arise where confidentiality not only can be breached but there may be an ethical or legal requirement to do so. Such occasions are the focus of this document.

The duty of confidentiality is owed to all patients, including mature and immature minors, and adults who lack the capacity to take decisions for themselves. The duty endures beyond the individual's death.

3.1.1 Breach of confidentiality

Logically, confidentiality can only be breached when the recipient of the information learns something that was previously unknown to him or her. It is not a breach of confidentiality to discuss the medical implications of general information which is already known by the recipient. Where relatives, for example, are already aware of an individual's condition or diagnosis, an explanation of the possible options for that patient does not breach confidentiality but revealing the person's views of those choices would do so.

Sharing information with patients about their *own* health and treatment is an essential part of good practice.¹¹ It cannot constitute a breach of confidentiality unless the disclosure entails revealing to the patient previously unknown information about another identifiable person, such as a relative.

3.2 Disclosure

The revealing of identifiable health information to anyone other than the subject.

Different interpretations abound, however, about what, in practice, constitutes a disclosure and many doctors assume that sharing patient information with other health professionals who have professional obligations of confidentiality neither counts as a disclosure nor requires consent. The BMA does not support this view. The matter was clarified to some extent by the Health Service Commissioner who stated that it is improper, for example, for a patient's previous doctor to have access to the record made after the doctor ceased to have care of that patient (although relevant parts of the past record can be disclosed to the doctor to defend his or her action in case of a complaint).¹²

The exchange of identifiable information between health professionals caring for a patient, unless the patient has expressly prohibited it, is essential (see definition of "need to know", section 3.5). The BMA does not accept, however, that such data can be routinely circulated to others simply because they are health professionals or are members of the "NHS family". Within all health care establishments, procedures should be in place to allow necessary access to identifiable data for the provision of care but preventing unrestricted access. Managers and administrators should not have routine access to identifiable data and should normally use anonymised data.

Although a wide awareness exists that the doctor-patient relationship may be damaged by improper disclosure of information about a living patient, the confidentiality owed to a deceased person is sometimes overlooked. Professional codes state that obligations of confidentiality extend beyond a patient's death although statute permits limited disclosure under the provisions of the Access to Health Records Act 1990 (see section 4.5.3).¹³

3.3 Personal health information

Any personal information relating to the physical or mental health of any person from which that person can be identified.

This includes all identifiable data relating to the provision of health care to an individual. Such information may be contained in medical illustrations, videos, tape recordings, computer files, genetic registers, disease management registers, manual records or held only in a doctor's memory. Information which is not clinical, such as a person's registration details with a particular GP practice, the fact of having attended a hospital, or a person's address, for example, is also confidential and patients should be made aware of any potential uses of information beyond their own care. Information which does not permit the recipient to identify an individual is not contentious. Coded, encrypted, aggregated or anonymised data can easily be used effectively for many health service or research purposes instead of identifiable data. It is good practice to use non-identifiable information wherever possible. Use of minimal data identifying the patient's electoral ward, sex and year of birth is acceptable for administrative or research purposes.¹⁴

From an ethical perspective, the BMA regards all identifiable health information as a special and sensitive category of data. The Association rejects notions of identifying certain types of health data as "particularly sensitive" and thus in need of particular protection, and believes that all personal information doctors learn about their patients should be afforded the same protection and be subject to the rules of confidentiality. It is noted, however, that in some circumstances the law makes such a distinction by imposing specific restrictions on the disclosure and use of certain types of information. For example, legislation governing information about fertility treatment sets the standard of consent necessary to permit information sharing at a higher level than is usually required, by requiring that consent be explicit in most circumstances.

3.4 Anonymised information

Information which does not, directly or indirectly, identify the person to whom it relates.

The BMA believes that from an ethical perspective, disclosure or breach of confidentiality occurs only when the information revealed can be linked to a specific individual. Anonymised data should be used wherever feasible. Care must be taken to ensure that any information which is thought to be anonymous is genuinely non-identifiable. Combinations of partial identifiers, initials, date of birth, sex, postcode, diagnosis, date of admission, can reliably identify many individuals, and expert advice should be sought before assuming that information containing any combination of such details is truly anonymous. Aggregating data will often serve to anonymise it.

Other identifiers can mean that information which appears anonymous actually is not since it can be linked to the individual to whom it relates in combination with other information available to the recipient. For example, information identified by only NHS number is identifiable to those people who have access to a database of NHS numbers. The BMA can see no way for the new electronic NHS to work other than giving this ability to link identity to NHS number to a massive number of people.

Throughout this guidance the BMA emphasises that disclosures of information should involve the minimum necessary to achieve the objective. Thus wherever possible,

anonymous or aggregated data should be used in preference to identifiable information.

3.5 Need to know

A 'need to know' justification applies to the sharing of information necessary to provide care or treatment for an individual patient.

Patients should be made aware that health teams need to share essential, relevant information in order to ensure that the safety and effectiveness of treatment are maximised. The sharing of identifiable data on the grounds of a need to know should be limited to those who have a demonstrable need to know it as part of their role in providing care. Within the BMA there has been considerable debate about how this works in practice and there is agreement that an overriding concern is for appropriate and effective care to be delivered to the individual patient. In the hospital context, for example, all health professionals directly involved, or likely to become directly involved in a patient's care should have access to the patient's record (unless the patient has expressly prohibited this) and restrictions which would potentially impede the provision of effective treatment in an emergency should be avoided. Wider disclosure, however, to people who may be only loosely associated with care, for example, to volunteer helpers, people gaining work experience, patient advocates or support staff in a residential care setting requires specific patient consent. This view was endorsed by the BMA's membership in 1999, when a proposal to permit free access to health information by all those involved in the management of a patient's care was turned down.¹⁵

From a legal perspective it has been suggested that the need to protect public safety might constitute a "need to know" justification although the law is not clear on this point.¹⁶ The BMA, however, sees public protection as a facet of the public interest in disclosure and not as justifiable by the perceived need to know. Some argue that research and administrative functions such as service planning fall within the need to know category of acceptable disclosures. Again, the BMA does not accept this. Where the desired objective can be achieved by suitably anonymised data, the BMA considers it imperative to do this. Otherwise it is necessary to seek patients' consent to the use of their information.¹⁷ Such consent may be implied where patients have been informed that their data may be so used and have not exercised their right to opt out (see section 3.7).

Health professionals should also focus on the objective of information sharing in any particular circumstance and make efforts to ensure that the recipient has information which is essential to achieve the objective but does not receive superfluous detail, particularly about matters which the patient considers sensitive. The third principle of the Data Protection Act 1998 requires that the personal data held must be adequate and relevant but not excessive for the purpose(s). The BMA emphasises that whilst it is impossible to define a general standard of "relevance" of information, it is unacceptable for doctors to keep (or share) unlimited information about patients.¹⁸ How much information is essential and who needs to know it are matters of sensitive professional judgement and awareness of patients' priorities. They should be discussed between health professionals and patients particularly if there is ambiguity or

conflict about the interpretation of "need to know" in a specific case.

Health information has secondary uses, such as planning, billing, teaching and audit, but it should be recognised that they are adjuncts to the main purpose, and therefore wherever possible (not merely where convenient) only anonymous health information should be used. As is emphasised throughout this document, managers, including those with a medical or nursing qualification, do not have a right of access to patient information simply by fact of their managerial responsibilities.

3.6 Consent to disclosure

The voluntary, specific and informed indication of wishes by which patients signify their agreement to identifiable information about themselves being given to others or used for certain known purposes.

For consent to be valid it must be a decision freely made in appreciation of its consequences.

3.7 Implied consent

Consent to disclosure can be taken to be implied when a patient, who is aware of the potential for sharing information and their right to refuse, makes no objection. Such a situation may arise where information is needed by a team providing care for a patient, or where a patient has been informed that information may be used for administrative purposes and has not exercised the right to refuse. In order for such consent to be valid, patients must have had a realistic opportunity to refuse, or opt-out. Leaflets, posters and letters can all be helpful in letting patients know about the potential uses of their information, although it is arguable that such methods may not be sufficient. Doctors must be aware of their responsibility to disclose information only with appropriate consent, and are advised to consider the needs of their own population of patients when developing steps to ensure that patients are suitably informed. When patients have indicated a refusal to allow their records to be used, this should be clearly noted in the health record and respected unless this would expose other people to harm.

3.8 The public interest

An exceptional situation where the right of an individual to confidentiality as contemplated by statute, case law and professional guidance may be overruled by society's interest in disclosure.

While the concept of an exceptional supervening public interest allowing some disclosures is widely acknowledged, nowhere is it closely defined.¹⁹ Outside the scope of obligatory disclosure covered by statute, each case must be considered on its merits. Nevertheless, bearing in mind that opinions vary about what can or cannot comprise a legitimate public interest disclosure, the BMA considers it vital that health professionals have as clear guidance as is possible about the parameters and limitations of the public interest justification. Much of this document is concerned with fleshing out the BMA's view of what disclosure in the public interest entails and reflects the Association's view of good practice.

3.9 Serious harm

In the latter sections of this document, attention is focussed on circumstances which might justify disclosure without the individual's consent. Principal among these is the risk of "serious harm" to identifiable individuals or to society at large. In the BMA's view, confidentiality is too important a principle to be sacrificed for vague goals or indefinable harms but it should give way where some "serious" threat to people looms. The BMA has identified threats to living people as significant in a way in which threats to property or financial interests are not. In line with this reasoning, the risk of an assault, a traffic accident or an infectious disease might be seen as more compelling grounds for disclosure than the risk relating to fraud or theft.

In reality, however, such neat divisions are not entirely satisfactory and in many cases, harm is multi-faceted. Serious fraud or theft involving NHS resources, for example, would be quite likely to harm individuals awaiting treatment. Even comparatively minor prescription fraud may reveal a serious harm if prescriptions for controlled drugs are being forged. Furthermore, since health professionals must always be prepared to justify their acts or omissions, their disclosure decisions must also reflect their views and conscience. Questions frequently arise, for example, as to whether GPs should report to officers of the Benefits Agency patients they suspect of illicitly claiming state benefits. The BMA's advice is that, wherever possible, doctors should raise the issue with the patient concerned and make it clear that health professionals will not collude with fraudulent claims, thereby encouraging the patient to desist from such action.

Even within the comparatively narrow sphere of harm to people, however, there is no broad consensus of how harm should be evaluated or from whose perspective it should be judged. For the victim who suffers harm or loss, it may be perceived in very different terms than for a decision-maker outside the situation who is trying to weigh it up. The BMA's advice is that, where feasible, health professionals should try to envisage the seriousness of the potential harm from the viewpoint of the person likely to suffer it.

In section 8.3, reference is made to the types of serious crime which would justify disclosure of information to the police. These include murder, manslaughter and rape. Serious harm, however, is a much wider concept than that of serious criminal activity and it encompasses omissions, such as neglect, as well as acts. It must also take account of psychological as well as physical damage. Child neglect or abuse is an example of treatment whose psychological sequelae may be considerably more profound than the physical harm suffered and the psychological damage may be experienced not only by the actual victim but also by siblings who know of it. When considering non-consensual disclosure, health professionals rightly take into account that the degree of psychological harm for victims may be influenced by the manner in which the disclosure is handled.

4 Disclosure with consent

4.1 The requirement for consent

Doctors do not breach confidentiality when they disclose information with their patients' permission, and this consent is the most common facilitator of disclosure. Guidance issued by regulatory bodies such as the GMC²⁰ and UKCC²¹ emphasises that in most circumstances identifiable health

information cannot be disclosed to third parties without the consent of the individual concerned. Professional rules and the law extend beyond the scope of the NHS. They govern private health practice as well as work for charities and for Home Office services such as prison, armed forces, immigration or police work, although in some cases specific legislation may supplement or supervene. The BMA firmly maintains that even where health professionals collect information for reasons which are not purely or even partly therapeutic, for example where examination is in connection with an insurance report, they still owe a fundamental duty of confidentiality, contravention of which requires patients' knowledge and consent.

4.2 The validity of consent

Disclosure with explicit consent by an informed adult is unproblematic although it is generally advisable that evidence of the patient's consent to disclosure to third parties, such as insurers or employers, be kept on the patient's file. In some exceptional cases, information can only be communicated between health professionals with the patient's explicit consent; for example communication between the health team at a fertility clinic and the patient's GP, or a genitourinary medicine clinic and GP, requires explicit consent from patients and cannot be taken to be implied.^{22, 23}

Health professionals often query the validity of an apparently uninformed or pressured consent, such as when a mature minor appears under pressure to allow parental access to his or her health record, or where information is being disclosed so the patient may enter into an insurance contract. In any case of doubt, it is advisable for health professionals to discuss the issues alone with the patient in order to obtain clarification. Patient consent to disclosure reported at second hand by potential recipients, such as employers, patient advocates or legal representatives, should also be verified with the patient unless a copy of the patient's signed valid consent has been supplied.

4.3 Implied consent: disclosure for purposes of care or treatment

The central reason for maintaining personal health records is to assist in providing health care for the individual patient. In the absence of evidence to the contrary, patients are normally considered to have given implied consent for the use of their information by health professionals for the purpose of providing the care they have come to receive. Information sharing in this context is acceptable to the extent that health professionals share what is necessary and relevant for the episode of care on a "need to know" basis. In the hospital context in particular, a range of health professionals have a demonstrable need to know information since care is provided by multi-disciplinary teams. Standards of care may be compromised if vital health information were to be withheld from care providers, although patients' refusals to permit sharing of information should be respected unless there are overriding reasons to prevent this such as those identified in this guidance. In such cases it is essential that patients are informed of the risks of non-disclosure (see section 4.4).

In order for the concept of implied consent to have any validity, it is important that patients are made aware that information about them will be shared and with whom, and

of their right to refuse. Since doctors bear responsibility for the disclosures they make, where consent is taken to be implied, doctors must be able to demonstrate that the assumption of consent was made in good faith and on good information. The BMA advises that leaflets and posters can play a part in conveying to patients the reality and necessity of information sharing within health teams.

It cannot be assumed that identifiable health information can be automatically shared with any other health professional or health service employee. Care must be taken to ensure that disclosures are not made inadvertently, that those receiving the information in a professional capacity also have obligations (professional, contractual and/or legal) to maintain confidentiality, that only information necessary to achieve the objective is disclosed and it is understood that the information should only be used for the purpose for which it is disclosed.

4.4 Refusal to allow disclosure

Sometimes two competing interests, such as an individual's informed refusal to allow disclosure and the need to provide effective treatment to that person come into conflict. A patient's refusal to allow information sharing with other health professionals may compromise the patient's safety but if this is an informed decision by a competent person it should be respected. Individuals may knowingly compromise their own safety but not that of other people. Health professionals, while not abandoning the patient, may ethically curtail the range of procedures they offer if the outcome might foreseeably be unsafe or ineffective due to lack of information, provided that patients understand this. Patients must be offered further advice if this is the situation.

Since the duty of confidentiality cannot be absolute, the right to refuse cannot be absolute. There are circumstances in which a competent refusal to permit disclosure might be overridden. This guidance identifies such areas.

4.5 Consenting for others

Confidentiality is owed equally to all patients regardless of their age, status or mental capacity. The fact that individuals are incapable of consenting (be it due to immaturity, temporary or permanent lack of capacity or an inability to communicate) neither implies that their information can be less closely guarded nor that it cannot be shared when it would clearly be in their interests to do so (see section 5).

4.5.1 Minors

Where an individual is an immature minor, disclosure can be authorised by a person with parental responsibility²⁴ provided that it is in the child's best interests. Young people mature enough to understand the implications can make their own decisions about disclosure, and have a statutory right to refuse to allow parental access to their health record under the provisions of the Access to Health Records Act 1990.²⁵

4.5.2 Mentally incapacitated adults

In some circumstances, the law allows a third party to authorise disclosure on behalf of a mentally incapacitated adult. Under the Access to Health Records Act 1990, where a person has been deemed incapable of managing his or her

property and affairs, access to the record can be given to any other person appointed the Court of Protection to manage those affairs. Similarly, where a proxy decision-maker has been appointed to take decisions relating to the management of property and financial affairs, this would include legal authority to authorise disclosure for benefits claims for example, or to pursue litigation. Currently there is no legal authority for any proxy decision-maker to give consent to medical treatment on behalf of an incapacitated adult in England and Wales. In Scotland, however, a tutor dative may additionally be able to take health care decisions on behalf of an incapacitated adult, although likely only to the extent that a decision was consistent with the best interests and previous wishes of the patient.

4.5.3 The deceased

The ethical duty of confidentiality extends beyond the death of the patient although legislation covering records made since 1 November 1991 permits limited disclosure in order to satisfy a claim arising from the death.²⁶ However, the legislation does not permit the disclosure of information which the patient gave on the understanding that it would not be revealed after his or her death, nor may the results of examinations or investigations be disclosed which the patient thought would be confidential at the time they were carried out. Where there is no evidence of a refusal to permit disclosure, information necessary to satisfy the claim may be released.

In circumstances where there is no claim, nobody can claim a legal right of access to information about a deceased patient, although doctors may consider disclosure to be justifiable based on the particular circumstances and knowledge of the patient's wishes. In all cases of posthumous disclosure the GMC recommends that the consent of the patient's executor or a close relative be sought.²⁷ Doctors should act in what they consider to be their patients' best interests, which may include giving consideration to the implications of disclosure and of non-disclosure.

5 Disclosure without consent in the subject's vital interests

It can be in the public interest, as well as in the interests of an individual, that a disclosure is made. Since people who are mentally competent decide for themselves when disclosure is in their interests, this section relates primarily to people who cannot express an opinion. Codes of practice allow for such disclosure in the subject's vital interests when there is no opportunity to consult the individual, such as in an emergency when the patient is unconscious or severely confused or is a young child or mentally incapacitated.

Other circumstances where disclosure is likely to be in the subject's interests but the person may be unwilling to consent to it arise in connection with abuse or neglect. Reducing abuse or neglect of vulnerable people, including children, the elderly or the mentally incapacitated is invariably in the public interest and is addressed below.

5.1 Emergencies

Disclosure should be made if it is necessary for the provision of emergency treatment or to avert an immediate and serious harm to any person. The BMA emphasises that

information can be disclosed where it is necessary to prevent or lessen a serious and imminent threat to the life or health of the individual concerned or another person. However, if the patient has previously made explicit that disclosure is not permitted, and has acknowledged the risks to him or herself, information must not be released unless essential to prevent another person from suffering serious harm.

5.2 Temporary or permanent mental incapacity

Mental capacity is a relative concept. Unless unconscious, most people suffering from a mental impairment can make valid decisions about some matters which affect them. In a joint publication on the assessment of mental capacity,²⁸ the BMA and the Law Society make clear that an individual's mental capacity must be judged in relation to the particular decision to be made.²⁹ Both bodies emphasise that people with a mental disability or illness can authorise or prohibit the sharing of information if they broadly understand the implications of so doing. Thus, if a patient has the requisite mental competence, disclosure of information to relatives or other people requires patient consent.

One of the most difficult dilemmas for health professionals concerns cases where the extent of the patient's mental capacity is in doubt. Relatives may report aberrant behaviour but if the patient refuses to cooperate with an assessment of his or her capacity, it is unclear to health professionals whether they are justified or not in providing medical information which would enable another person to act in the patient's interests. The BMA's advice in such cases is that health professionals must assess the information which is available from the patient's record and from third parties. They should attempt to discuss with patients their needs and preferences and weigh up whether the patient appears to be making a valid refusal regarding the assessment or the sharing of information resulting from it.³⁰

If a patient lacks the ability to understand, decisions must be based on an evaluation of the incapacitated person's best interests which should reflect the individual's current or previously expressed wishes and values. Disclosure of information about mentally incapacitated patients may be essential for their protection or wellbeing, or may permit a lawyer or advocate acting on the patient's behalf to further the patient's interests. The Access to Health Records Act 1990 gives a statutory right of access to the records of a patient incapable of managing his or her affairs to a person appointed by a court to manage those affairs.³¹

Outwith the legal authority to consent to disclosure on behalf of an incapacitated adult (see section 4.5.2), doctors have always had a discretion to release information when it would clearly be in the incapacitated individual's interests to do so and the person has not expressed an objection. Release of records for litigation or in pursuit of compensation on behalf of the incapacitated person are examples of where disclosure is likely to be both in the interests of the patient and in the interests of justice.

Safeguards must be in place to ensure that information about incapacitated individuals is not treated less securely than that of other patients. Any decision to disclose must be justified either on the grounds that the recipient has a demonstrable need to know for the care of that person, or it is in the person's best interests or, exceptionally, because

the public interest requires it (see section 8). As with all patients, health professionals may have to consider breaching such patients' confidentiality, even in the face of patient opposition, if there is a strong likelihood of serious harm resulting from their silence.

5.2.1 Mental health legislation

The fact that patients are detained under the mental health legislation does not imply that they cannot make valid decisions about disclosure. Many detained patients make valid decisions with regard to disclosure and these must be respected in the same terms as those of other patients. Preservation of confidentiality must be the norm, and be overridden only where there is proper justification for so doing.

It should be noted that the Mental Health Act 1983 includes some statutory requirements for disclosure. For example the Act requires disclosure of medical records to the medical member of a Mental Health Review Tribunal which is considering exercising its powers of discharge in relation to a detained patient. Disclosure here is not only usually in the patient's interest but is also a statutory requirement.³²

5.2.2 Mental health services

For many patients with learning difficulties or mental disorders, care will not be provided in hospital or under the specific provisions of legislation, but will be provided in the community. Personal health information may need to be shared with other professionals in order for patients who are cared for in the community to receive the support and care they need.

Outwith the provisions of legislation, non-statutory initiatives ensure communication between those involved in providing care. This is an example of a situation where the requirement to disclose information is also likely to be in the interests of the individual as long as health professionals limit disclosure to those with a clear "need to know". Information about people with mental illness who may be a significant risk to themselves or others, for example, should generally only be available to mental health professionals who need it to provide care and other professionals with responsibilities to the patient, including the GP. Disclosures to other people may be justified on the grounds of a public interest in preventing harm. Any central store of information such as this must be securely managed.

Disclosures to others, such as social services, independent sector care providers, representatives, carers or near relatives of the individual may be made in cases where:

- it is clearly in the individual's interests; and
- it is impractical or impossible to obtain the individual's valid consent; and
- the disclosure is not contrary to the individual's express request or known wishes.

6 Obligatory disclosure

In any situation where disclosure is made in the absence of the subject's consent, careful consideration must be given to the question of to whom it is proper to disclose. This will vary with the circumstances of the case and the objective which is sought. Indiscriminate disclosure is never justifiable. Where there is a statutory requirement for disclosure, the

recipient of the information is usually identified and in such cases the information released should be the minimum to fulfill the requirement. It should not normally involve transfer of an individual's entire record.

A range of non-consensual disclosures are properly made to courts or other authorities because a statutory duty exists. If health professionals have any doubts about whether the disclosure requested by police, lawyers or others is a statutory obligation, they should ask the person or body applying for the information to specify under which legislation it is sought. Similarly doctors and their representative bodies will wish to question statutory requirements where these appear contrary to ethical principles (see, for example, section 6.3).

6.1 Disclosure required by statute

Many of the examples of statutory disclosure involving doctors entail sensitive health information, such as the requirement under the Abortion Act 1967 to provide the name and address of the woman concerned. Where a statutory requirement exists, the patient's consent to disclosure is not necessary, and the patient has no right to refuse, but he or she should be told of the fact and purpose of the notification, and reassured that disclosure will only be to a secure authority.

The following are given by way of illustration.

6.1.1 Occupational health

Occupational health provides a number of examples of statutorily required disclosures both by health professionals and about them. Occupational health professionals carry out examinations which are related to statutorily defined standards of fitness. Disclosure of information in such cases is a requirement to which the subject must consent as a condition of being employed. It should always be made clear to the individual that in such cases, medical examination is not within the normal therapeutic relationship and that information resulting from it will be disclosed. If the patient refuses to authorise disclosure, the doctor must inform the potential employer of this, and the individual may risk not being considered for the employment.

The Control of Substances Hazardous to Health (COSHH) Regulations are industry-wide measures which are controlled by the Health and Safety Executive. They provide legal controls on all forms of substances hazardous to health in all work settings. Employers are required to assess and control risks to health arising from exposure to hazardous substances and inform employees about them. Biological agents and body fluids can represent risks which should be reported under the COSHH regulations. Likewise the immune status of health professionals must be declared on a need to know basis to enable the employer to carry out the general duty of care by removing the vulnerable worker from exposure to a quantified risk. Refusal by an individual to disclose a medical condition foreseeably likely to affect seriously the health and safety of the individual, other employees, contractors and members of the public must disqualify that individual from undertaking the duties which carry such a risk.

6.1.2 Laws affecting all citizens

In addition to laws specifically requiring disclosure from health professionals, they may also be affected by the disclosure statutes which affect all citizens. Examples are the obligation under the Prevention of Terrorism (Temporary Provisions) Act 1989 to inform the police of information about terrorist activity, and the Road Traffic Act 1988's requirement to provide the police, on request, with information which might identify a driver alleged to have committed a traffic offence.

6.2 Disclosure required by a court

The courts, some tribunals and persons appointed to hold inquiries have legal powers to require that information which may be relevant to matters within their jurisdiction be disclosed.

When a patient has not given consent for the disclosure of medical records, health professionals are nonetheless justified in disclosing information when they believe on reasonable grounds that a court has authorised it. Where a court or tribunal so orders, health professionals or bodies must disclose strictly in the terms of that order. That is to say, for example, that if the order requires disclosure to the court, the information should only be handed to the court.

Sometimes the health professional may experience a conflict of duties if a court demands information, disclosure of which conflicts with ethical obligations. Such conflicts can arise, for example, when the court order requires disclosure of sensitive health information provided in confidence, especially if the doctor believes it is not germane to the case. Or disclosure of the record may also reveal personal health information about a third party, such as the patient's relatives. In such cases, doctors should make their ethical objections known to the judge or presiding officer. If, however, the judge decides that the information must be released, doctors risk being found in contempt of court if they refuse to comply. Where disclosure is ordered by a court the patient should be informed of this development as soon as possible and ideally before the disclosure is made.

6.2.1 Disclosure for litigation purposes

The Access to Health Records Act 1990 is the usual route by which records are made available for litigation purposes. Additionally sections 33 and 34 of the Supreme Court Act 1981 empower courts to order the disclosure of medical records for the purposes of litigation to:

- an actual or potential litigant;
- his or her legal adviser; or
- any medical or other professional adviser nominated.

Discretion regarding the person to whom disclosure should be made lies with the court. In such cases health service bodies holding records need not formally obtain the consent of the subject or of the responsible health professionals, although they should give those persons prompt notice of the order so that they can have an opportunity to apply to the court or tribunal to have it set aside if they so wish and circumstances permit.

The courts may also order that an action be stayed where a patient making a claim of negligence refuses to allow access to relevant medical records. In one case where a patient refused to waive her right to confidentiality and give consent for access to relevant parts of her medical records,

it was ordered that unless she did so, the action would be stayed.³³

6.2.2 Disclosure in criminal cases

Where a doctor has refused to release medical records for use in criminal proceedings, for example because the patient has not given consent, the person seeking the information may apply to the court for a witness summons to be issued requiring the doctor (or other third party) to produce the information. This is covered by rules on third party disclosure, introduced in the Criminal Procedure and Investigations Act 1996, which came into force on 1 April 1999. The rules place the onus firmly on the person seeking disclosure to justify the issuing of a witness summons. Applicants are required to state specifically what information they require, why they believe the third party holds the information and why it is material to the case. They must also state why it is considered that the witness will not provide the information voluntarily. The witness (which could be a doctor when the information sought is personal health information) is given seven days to notify the court that he or she wishes to make representations, either in writing or at a hearing. If a hearing is requested the doctor will have the opportunity, either personally or through a representative, to draw attention to the duty of confidentiality, or to argue that the information requested is not material to the case. If, having heard the evidence, the judge issues the witness summons, however, the information must be provided or the doctor risks being found in contempt of court.

6.2.3 Disclosure to a coroner's court

The coroners' courts have a statutory right to require the supply of information which could include personal health information. Health service bodies are not required to obtain consent in order to comply with any direction to supply data to a coroner's court. Again, though, they should notify individuals concerned and the responsible health professional where reasonably practicable. In cases of doubt the health service body's legal advisers should be consulted.

6.3 Military law and regulations

Military law and regulations have long required personnel to inform their commanding officer if a member of the forces is known to be homosexual. This obligation applied to military doctors. The BMA and GMC have strongly opposed this requirement, acknowledging that the duty of confidentiality cannot be absolute, and that there is a duty to disclose information when an individual poses a threat to the health or safety of the public at large, similarly to colleagues or to a military unit. This might arise, for example, when a member of the forces is addicted to drugs or alcohol. Doctors should, however, be able to exercise clinical discretion about health issues which require such reporting. The BMA does not consider that sexual orientation alone, without other indicators of a risk to others, is relevant information for doctors to disclose.³⁴

6.4 Disclosure by police surgeons

The duty of confidentiality owed by police surgeons is the same as that owed by any other doctor. The only information which is routinely disclosed is that which forms the report the doctor prepares for the purpose of criminal proceedings.

Thus information gained by police surgeons in the course of their forensic examination which is not germane to the case must be accorded the same protection as any other information obtained by health professionals. Specific, detailed guidance on the role of the police surgeon is available from the BMA and is summarised below.³⁵

- Care should be taken to explain, before the examination takes place, the police surgeon's role and the extent to which confidentiality may be limited or maintained.
- Doctors should balance considerations of personal safety with those of confidentiality, remembering that the confidentiality of information provided in the presence of a third party is not guaranteed under procedures and codes.
- Statements prepared for the police should contain only forensic information and any other information which is likely to affect the outcome of the case.
- Any other information obtained during the examination (eg medical history or therapeutic information) should not be included in the report. This information should remain confidential unless the individual gives consent to its release, its disclosure is ordered by a court or a public interest justification exists for its release (see section 3.8).

7 Other disclosures and their safeguards

7.1 General Principles

- Information disclosed should be the minimum necessary to achieve the objective and, wherever possible, anonymous.
- Patients should be made aware of the potential uses of their information, and be given an opportunity to object.

7.2 Sources of safeguards

Health records are a potent source of information, upon which many demands are made. This section of the guidance addresses situations where disclosure may be requested for purposes related to the effective provision of care, such as to further medical knowledge and to investigate complaints. Quasi-legal and professional guidelines provide some guidance and protection in these cases.

7.2.1 Quasi-legal requirements

Quasi-law³⁶ means standards to which health professionals are expected to adhere, contained in, for example, guidance from non-statutory professional bodies, health service circulars and executive letters, even where these are not legally binding. These may have varying degrees of legal force by virtue of the manner in which they set standards, or of their relationship to statute. In practice, they are very influential and usually can be seen as representative of a responsible body of opinion within the health professions. Department of Health guidelines on the requirements for research ethics committee approval of research, and on the retention of health records are examples of quasi-legal rules in relation to confidentiality.^{37, 38}

The fact that guidance has been issued does not, however, necessarily resolve the dilemmas for health professionals

since the guidance itself may not be the subject of widespread consensus. An example can be seen in a paper from the Royal College of Physicians regarding the use of patient records in research.³⁹ The paper, published in the BMJ was based on the assumption that clinicians carrying out records based research did not require consent from the data subject or authorisation from any other body, such as a Local Research Ethics Committee. Bodies such as the BMA rejected the guidance, which also contradicted the Department of Health's advice. Nevertheless, health professionals who act in accordance with a reputable body of opinion are likely to be protected from litigation⁴⁰ (provided that the guidance itself does not recommend acting unlawfully) but should take reasonable steps to ascertain whether the guidance they are following is still current within the profession.

7.2.2 Professional requirements

The guidance of professional regulatory bodies, the GMC, the UKCC, must be followed by health professionals in order to remain on the professional registers which permit them to practice. Failure to comply with the regulatory body's standards can lead to disciplinary proceedings, with sanctions including restriction of practice, suspension and being struck off the register. Throughout this guidance the advice of the GMC is referred to and built upon to offer detailed guidance and explanation to doctors.

7.3 Adverse drug reactions

Mechanisms exist for the routine reporting of adverse drug reactions to the Medicines Control Agency. The reporting system requires the inclusion of the patient's name, sex and date of birth as well as details of the reporting health professional. This information is used to find instances of duplicate reporting of the same incident, and is tightly controlled at the MCA so that free access to identifiable information is not available. Doctors have both ethical and legal responsibilities for the reporting of adverse drug reactions, and should let their patients know of these obligations whilst reassuring them of the safeguards to prevent inappropriate access to the information.⁴¹ The BMA is also aware of instances of pharmaceutical companies seeking this information from GPs, since it is clearly of interest to them. The BMA advises that identifiable information should never be disclosed in such circumstances, without specific, unpressured consent.

7.4 Research

Detailed and widely accepted guidance on research has been issued by a range of bodies, such as the Royal Colleges, BMA, GMC, Association of the British Pharmaceutical Industry and Committee on Publication Ethics⁴² and the provisions of the Data Protection Act 1998 also cover research. For the purposes of this document it is perhaps unnecessary to define in detail the manner in which research can be justified but simply to note that use of information for research is currently accepted as long as it is carried out within the guidelines and subject to monitoring by appropriately constituted research ethics committees. It is strongly recommended that patients be made aware that research is carried out, and that this may involve the use of their records unless they object.

While it can constitute a justifiable use of personal health information, research should ideally use anonymised data

wherever possible. It may be possible for to use pseudonyms or other tracking mechanisms for information which cannot be anonymised, thus ensuring accuracy and minimising the use of personal identifiers. Health professionals must make reasonable efforts to ensure that patients understand that their data may be used in research unless they exercise their right to object. Identifiable information should not be used for research purposes if the individual has registered an objection. Nor should the contact details of potential participants in research be passed to researchers without consent. A common enquiry to the BMA comes from doctors who are asked to release the contact details of potential participants to researchers. The BMA considers this to be unacceptable without patient consent, and advises instead that the initial approach to patients should be made by the patient's doctor.

Where doctors are asked to release information for ethics committee approved research, but have doubts about whether the issues of confidentiality and consent to disclosure have been fully addressed, information should not be disclosed until the issue has been cleared up. For example, doctors may be aware of specific circumstances relating to their population of patients, or to individuals, which may not have been brought to the attention of the approving committee. The BMA asks doctors to bear these matters in mind when they are asked to disclose information, and to ensure that any disclosures can be justified.

Safeguards for the ethical conduct of research, identified in consultation with the GMC and Medical Royal Colleges, can be summarised as follows:

- Research both within and outside the NHS must be subject to approval by an appropriate research ethics committee in compliance with clear confidentiality rules. Research ethics committees must be constituted in accordance with current guidance.⁴³ Only after approval by the committee can information be released to researchers. Wherever possible, anonymised data or data with coded identifiers should be used.
- Mechanisms should be in place to record and give effect to any patient's refusal to allow identifiable data to be used in research. Patients can be encouraged to agree but must also be aware of their right to object.
- All researchers and research organisations must have secure methods of storing data.
- Staff who work with confidential data as part of research projects must be trained and their performance evaluated to ensure respect for confidentiality and security procedures.
- The research community and other health professionals should develop and support mechanisms for notifying the public about the benefits and objectives of research projects.
- Information must not be published in a form that could reasonably be expected to identify any individual subject without the express consent of that person (or that person's representative where the law recognises the validity of the representative's consent).

7.5 Clinical audit

Clinical audit should be carried out by health professionals with clear professional obligations to maintain confidentiality. It is good ethical practice to take steps to inform patients that the quality of care is reviewed through the process of audit and that this might involve looking through a patient's records to produce anonymised audit data. If patients express a refusal to allow their information to be used for audit purposes, this should be respected.

The BMA has no ethical objections to anonymous records being used for clinical audit purposes without consent, provided that the process of removing identifying details is carried out by a member of the health care team involved in treating the patient. Where no additional individual has access to records, no breach of confidentiality can occur. Where access to identifiable information is required by other individuals, for example audit professionals in hospitals, consent to disclosure must be sought. Such consent may be gained by providing patients with information about the fact and purpose of audit, and giving them an opportunity to refuse to allow their records to be disclosed.

Increasingly, hospitals, Trusts and GP surgeries are commissioning health professionals (and sometimes others) to carry out audit on their behalf. Commercial agencies are also becoming involved in audit and commissioners of such services must ensure that employees have firm contractual, in addition to any professional, obligations with regard to the preservation of confidentiality. Where a third party is to be brought in to carry out audit, there must be added safeguards to ensure that confidentiality and anonymity are preserved. Ideally, information should not be released to people who do not have an enduring professional responsibility to maintain confidentiality. The BMA recognises that this may not be practical in all cases, but health professionals should aim for maximum protection for patients.

Outside bodies, such as pharmaceutical companies, are also sometimes interested in sponsoring the audit of aspects such as prescribing habits in return for basic information resulting from the project. Doctors approached to participate in such arrangements should seek advice from the GMC and BMA about whether accepting the services of a health professional from a pharmaceutical company would be in breach of the GMC's guidance.⁴⁴ Where such an arrangement is contemplated, doctors should enquire about the uses to which such information is likely to be put and ensure that no identifiable data leaves the health care organisation. This requires monitoring not only that patient names and addresses are excluded, but also that other identifiers are excluded to ensure anonymity. Doctors should also be aware of the legal issues around the disclosure of anonymous information (see section 1.4).

The lengths to which it will be necessary for health professionals to go to seek patient consent will depend on the circumstances of the audit and who will require access to the identifiable information. A spectrum of options exist. For example, if patients are made aware that audit is carried out, and that the process might involve other health professionals in the practice or hospital who have not been involved in their care anonymising the records, provided there is a real opportunity to refuse to participate the BMA can see no ethical objection to the audit proceeding.

However, the Association advises that additional safeguards may be needed when access to identifiable information will be by non-health professionals, or by individuals from outside the health care organisation.

7.6 Teaching

Teaching is an essential process but, in the BMA's view, it is contrary to the public interest to use identifiable material for teaching purposes without the subject's consent. Patient-identifiable materials cannot be used without consent even in the context of teaching hospitals, although the Association has no ethical objection to anonymous information being used in teaching.⁴⁵

Where an individual is unable to give consent, information may be used where there is consent from a proxy legally entitled to give consent on the patient's behalf (somebody with parental responsibility for a young child, for example, although consent should be sought from the young person once he or she is able to give it if identifiable materials continue to be used). In other cases, the BMA considers it acceptable to involve people unable to consent in teaching, provided that involvement is not contrary to the known wishes of the patient, and that the same objective could not be achieved with patients able to give consent. Health professionals should discuss involvement in teaching with those close to the patient. This might include a nominated representative or advocate, spouse, principal care giver, next of kin, close relative or other person whom it is, in the opinion of the health professional, reasonable in the circumstances to ask. The purpose of discussion is to ascertain whether involvement in teaching would be contrary to the interests of the particular patient, given his or her ascertainable preferences.

The BMA has issued separate guidance on the issues of confidentiality which arise when potential medical students observe medical practice, this is available from the BMA's Career Progress of Doctors Committee.⁴⁶

7.7 Disease registers

Disease management registers are databases holding information about patients usually for purposes of that patient's care. Registers may also be used to provide non-identifiable information for planning the use of health service funds and for research. An example would be a register holding information about diabetic patients, which included information about care plans and correlated this with information about use of health care services. It can thus be used to monitor that individual's health, and the information can be used to make comparisons between different care plans and whether these lead to differences in the need to access health care services.

Often the relevance and usefulness of registers is questioned, and it is important for all doctors becoming involved with the development or use of a register to ensure that it does fulfil a useful function, and does so safely and effectively. With any register, the issue of confidentiality must be addressed. It is essential that patients' consent is sought for the inclusion of any identifiable information on registers. It must be explained to patients why the register is held, for what purposes the information may be used, and that they have a right to refuse to be included or to restrict the use of their information to certain specified purposes.

Identifiable information should only be held on registers where this is necessary to fulfill the register's function. If the aim of a register is primarily administrative for example, it may be sufficient for the information it holds to be anonymous. Where it is not possible to hold only anonymous information, for example because updating of information and monitoring of individual patients is intended, it may be possible to use a system of unique patient identifiers known only to the health professionals involved in treating the patient. This can mean that the register can also be used to produce anonymous information for planning or administrative purposes.

Where registers might include information about young children who lack the capacity to give valid consent to inclusion on the register, consent should be sought from a person with parental responsibility, and confirmed with the young person when he or she is able to give consent. Information may be included about mentally incapacitated adults only if this is in their best interests and they do not object.

7.7.1 Genetic registers

Genetic registers usually hold information about those affected by a particular genetic disorder. Some genetic registers have an additional purpose; to contact family members of those on the register. This should be explained when consent is sought for inclusion. If relatives are contacted they should then be asked to give consent themselves for information about them to be held on the register. If they refuse, the information should be deleted.⁴⁷

7.8 Complaints

Reasonable efforts must always be made to obtain consent before identifiable health information is used to investigate or adjudicate a complaint, unless to delay may put other people at risk. In some cases, however, that person may be dead or untraceable. Some individuals may refuse to have their information used for such a purpose and their views should be considered with due respect but, depending on the gravity of the complaint, the public interest in protecting other people may require disclosure. The GMC has powers to require the production of medical records for its investigation of complaints as part of performance procedures involving doctors.

7.9 Planning, administration and purchasing

It is generally the case that aggregated or anonymised patient information should be used whenever it is possible to do so and still achieve the desired objective. Therefore the management, administration and planning of health care services should primarily rely on such forms of data. Occasionally, however, proper management by a health service body necessitates access to identifiable personal health information. All reasonable efforts must be made to make patients aware of the necessity of these functions. They must also be given an opportunity to refuse.

In keeping with its advice throughout this document, the BMA does not consider it to be acceptable to use patient's health records for administrative purposes without consent. From an ethical perspective, consent cannot have any validity unless patients are aware of the potential uses of information, and are given a real opportunity to opt out.

Patients should thus be made aware, by whatever means are necessary, that information may be required for administrative purposes. For example, this may be drawn to the attention of all patients on registration with a new GP, on attendance at hospital, or by letter. Notices, leaflets and posters can also be useful, but may not be sufficient on their own to ensure that all patients are informed (see section 3.7).

7.9.1 Financial Audit

The BMA does not accept that it is routinely necessary for financial auditors to have access to identifiable patient information in order to verify the appropriate use of NHS resources. Similarly, the Association prefers that any person having access to identifiable health information should be bound by the rules of a statutory regulatory body, in order that appropriate means of redress are available should confidentiality be breached (see section 10.1 on the need for legislation). However, since not all health authority staff who currently undertake inspections to verify claims for payment have professional registration and this should be clear to patients.

The Association therefore supports the GMC's published view that patients must be informed prior to their records being used for financial audit:

- i. *About the purpose of such disclosures.*
- ii. *That the auditor may or may not be medically qualified.*
- iii. *That they have a right to object, and that such objections will be respected.*⁴⁸

The BMA's General Practitioners Committee has issued advice for GPs on the practicalities of seeking consent for disclosure for financial audit.⁴⁹

8 Disclosure in the public interest

Advisory bodies, such as the BMA, cannot tell doctors whether or not to disclose information in a particular case, but can provide general guidance about the categories of cases in which disclosure decisions are justifiable. The fundamental aim of this section is to provide assistance by outlining exceptional circumstances where personal health information may be disclosed properly without consent because there is perceived to be a strong public interest justifying disclosure. Disclosure which is essential to prevent or lessen a serious and imminent threat to public health or to the life or health of another individual typifies this category of justification.

8.1 General principles

When considering disclosing information to protect the public interest, doctors must:

- consider how the benefits of making the disclosure balance against the harms associated with breaching a patient's confidentiality;
- assess the urgency of the need for disclosure;
- consider whether the subject might be persuaded to disclose voluntarily;
- inform the subject before making the disclosure and seek his or her consent, unless to do so would enhance the risk of harm or inhibit its effective investigation;
- reveal only the minimum information necessary to achieve the objective;

- seek assurances that the information will be used only for the purpose for which it was disclosed; and
- be able to justify the decision.

8.1.1 Balancing benefits and harms

Often a decision to disclose will not be based on the interests of the subject but is made to protect other people or the public at large. The decision to disclose is based partly on a balancing of several moral imperatives, including the risk and likelihood of harm if no disclosure is made, and the need to maintain the trust of the patient. Health professionals can be in an invidious position in having to weigh speculative as well as known facts and assess whether a perceived harm can be better averted by making a disclosure or by maintaining the trust of an individual while attempting to persuade him or her to disclose voluntarily. It may be helpful to discuss situations on an anonymous basis with colleagues, and/or to seek advice from professional and indemnifying bodies.

In some cases, although a duty of confidentiality is owed, the need to protect other people may tip the balance. Sometimes, for example, post-mortem testing of a cadaver may reveal the presence of previously undiagnosed infectious conditions which people close to the deceased person may need to be aware of in order to protect their own health or that of others. In cases of a clear and serious threat to health, a strong moral argument can be made for disclosing information to obviate that threat.

In many cases, however, clear and unambiguous information upon which to judge the scope of the potential threat is unavailable. Scraps of information may be pieced together but, even after discussion with the patient and with experienced colleagues, it may be impossible to ascertain the degree of actual risk in order to make a fair and justifiable decision to disclose. Time, patience and repeated discussions with the individual may be needed to clarify the real dimensions of the threat. Non-consensual disclosure is generally only considered justifiable in cases where the threat appears serious and imminent and disclosure is likely effectively to limit or prevent it occurring.

8.1.2 The urgency of the need to disclose

In all cases, delay is inadvisable where the risks are imminent, serious and foreseeable. Health professionals who are unable to persuade an individual to disclose voluntarily information which could prevent serious harm to other people are likely to be justified in disclosing without consent.

8.1.3 Involving the subject

It is desirable for individuals to be strongly encouraged to take responsibility for disclosure themselves whilst being made aware that a reluctance to do so may oblige the health professional to take action. Persuasion may require time, counselling, repeated consultations and possibly discussion of the case on an anonymous basis with colleagues or with other agencies. Health professionals must therefore weigh up the potential immediacy of the risk in relation to the likelihood of eventually persuading the individual and consider whether the objective of preventing harm is achievable by other means.

In some cases, it is clearly inadvisable to alert the individual to the fact that health professionals are considering disclosure. Such cases arise, for example, when telling him or her would exacerbate the threat, possibly also resulting in violence against the health professional, or it might give time to destroy evidence necessary to secure the long term protection of the other people at risk.

8.1.4 Making a disclosure

Decisions to disclose information in the public interest should be taken by health professionals, not other health service staff, and may involve discussion amongst the whole health care team. Whenever possible, the clinician with overall responsibility for care must be consulted.

Disclosure without consent should only reveal the minimum of information required to deal with the risk and careful thought must be given to the question of to whom the information should be released. This is likely to vary according to the circumstances of the case.

A doctor must be prepared to justify any decision regarding disclosure, and may be asked to do so before the GMC.

8.1.5 Seeking advice

Health professionals should remember that advice can always be sought from professional and indemnifying bodies, which are able to advise on whether the decision accords with current professional expectations.

8.1.6 Whistleblowers - responsibilities and protection

A genuine concern for those considering disclosing information is the repercussions a disclosure might have for themselves. Throughout this guidance it has been emphasised that doctors risk criticism as much for disclosing inappropriately as they do for not disclosing when to do so would be in the interests of the public.

Similarly, employees will often be the first to see or suspect misconduct or dangerous practice but may be reluctant to take action for fear of jeopardising their own position. Whilst taking action is not easy, the BMA and GMC encourage doctors to do so where they consider it justified. The GMC's advice states that:

'You must protect patients when you believe that a doctor's or other colleague's health, conduct or performance is a threat to them.'

Before taking action, you should do your best to find out the facts. Then, if necessary, you must follow your employer's procedures or tell an appropriate person from the employing authority, such as the director of public health, medical director, or chief executive, or an officer of your local medical committee, or a regulatory body. Your comments about colleagues must be honest. If you are not sure what to do, ask an experienced colleague or contact the GMC for advice. The safety of patients must come first at all times'.⁵⁰

Where disclosures are justified in the public interest, doctors ought to be assured of the support of their professional bodies, and can also invoke the law should difficulties following a disclosure arise. The Public Interest Disclosure

Act 1998 concerns the need to protect individuals who make certain disclosures of information in the public interest and to allow such individuals to bring action in respect of victimisation. The BMA has, in the past, reported barriers to a culture of openness stemming from competition and market attitudes within the NHS, where employers sought to give pre-eminence to clinicians' loyalty to the organisation and shifted the notion of confidentiality from a duty owed to patients to one owed to the health care system.⁵¹ The BMA thus welcomed the legislation, and sees it as providing welcome and needed protection for whistleblowers which should encourage the early identification of situations which put people at risk. Medical students should not assume that they are protected by the legislation, since its provisions cover only those students who are on work experience placements. Students should seek advice from their medical school, the GMC or a relevant professional or advisory body.⁵²

An intention of the Act is to channel discussion through appropriate sources. Disclosures which qualify for protection include those where the disclosure is made to the employer or in accordance with a procedure authorised by the employer. The BMA receives frequent enquiries about who is the appropriate person to make a disclosure to, and recommends that places of employment should have an in-house code of practice concerning disclosures relating to the workplace.

Doctors should also look to their indemnifying bodies for support, but it can be important to have discussion in advance with these bodies to consider whether the proposed disclosure is the best way to proceed.

8.2 Serious harm

Health professionals have clear moral duties to individual patients and to colleagues which may come into conflict with wider obligations to avert serious and preventable harm to others in society. What may constitute serious harm is discussed briefly in the definitions section of this guidance although it is acknowledged that evaluations will vary according to the circumstances of the case. Further examples of situations involving the potential for serious harm are given in section 9.

In general practice, where a patient has information concerning a risk to identifiable others, the situation may be complicated by the fact that those others may also be patients of the same GP and owed a duty of care. In such cases, doctors sometimes resort to complex strategies to empower the person at risk to protect his or her own health and wellbeing, without breaching the confidentiality of the non-disclosing patient. Patients may refuse to divulge to sexual partners information about sexually transmitted diseases, for example, or refuse to share information about genetic testing with relatives who could benefit from knowing it. It may sometimes be possible to avoid the need for non-consensual disclosure by counselling and providing general information to the person who may be at risk.

Where this has not been possible, however, in some circumstances doctors will be justified in breaching confidentiality in order to prevent serious harm. The GMC, for example, advises doctors that they "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".⁵³

The same considerations apply to circumstances where the potential disclosure relates to a colleague who poses a threat to the health of his or her patients by reason of illness, incompetence or addiction (see section 8.6).

8.3 Serious crime and national security

Disclosure necessary for the prevention, detection, investigation or punishment of a serious offence is widely regarded as justifiable and desirable. The definition of what constitutes a "serious" crime is a matter of debate. The Police and Criminal Evidence Act 1985 contains some definitions of what it calls a "serious arrestable offence", that is one which has caused or may cause serious harm to the security of the state or to public order; serious interference with the administration of justice or with the investigation of an offence; death; serious injury; or substantial financial gain or serious loss.⁵⁴ These definitions include such crimes as murder, manslaughter, rape, treason and kidnapping. Generally, crimes which may result in serious harm or loss of life for individuals can be regarded as very substantially more significant than crimes involving theft, fraud or damage to property.

The BMA recommends that in such cases, health professionals should seek advice from their professional, disciplinary and indemnifying bodies. Further discussion, provision of counselling or therapy for the person alleging the offence, whether that person claims to be either the victim or the perpetrator, may clarify the issues.

Before disclosure of any information is made the following conditions should be satisfied:

- the crime must be sufficiently serious for the public interest to prevail;
- it must be established that, without the disclosure, the task of preventing or detecting the crime would be seriously prejudiced or delayed;
- the information is not available from another source which would not necessitate a breach of doctor-patient trust; and
- satisfactory undertakings must be obtained that the personal health information disclosed will not be used for any other purpose and will be destroyed if the subject is not prosecuted, or is discharged or acquitted. DNA samples, for example, may be taken as part of a criminal investigation but should not be retained by the police after an individual has been exonerated of any criminal activity.

These conditions should be applied to consideration of any disclosure in connection with a crime. Commonly a source of enquiry to the BMA is the situation in which many GPs find themselves, where the police are investigating a crime near the practice premises and want to know who attended the surgery in a given time period. The fact of attendance is, in itself, confidential and should not be disclosed unless disclosure can be justified according to the criteria set out above.

Similarly, doctors are often asked to speculate on the identify of the perpetrator of a minor crime, such as theft of personal belongings from health care premises. It is unlikely that such crime would be considered to be of sufficient severity to warrant a breach of confidentiality. The police do not have an automatic right of access to information, and advice can always be sought from professional, regulatory or indemnifying bodies where there is any doubt.

Local liaison procedures for health professionals and the police would facilitate arrangements for disclosure in such circumstances and the BMA supports the development of detailed local procedures on disclosure. Such an approach would also serve as a reminder that the police do not have an automatic right of access to the information held by doctors. In the BMA's view, decisions about disclosure of health-related information should be taken by the health professional responsible for the relevant aspect of the patient's health care at the time, in consultation with an appropriate officer of the health service body. It is strongly recommended that a record of all such disclosures be kept.

8.3.1 Crimes in the past

While it is widely accepted that information should be disclosed to prevent or detect a serious crime, or bring to justice the suspected perpetrator before the crime can be repeated, it is sometimes argued that the obligation to disclose is weakened if there is no continuing danger. Whereas the justification for disclosing information about a serious, current or future threat is clear, the public safety justification for doing so in regard to a past offence is less so if the individual is unlikely to repeat it. Such arguments have been raised with the BMA in relation to either confessions or allegations against others of past child abuse or "mercy killing". As in all other cases, doctors need to assess the particular situation, and may find it helpful to take advice from professional and indemnifying bodies.

In general, however, health professionals should be very wary of concealing any information of substance which would lead to the resolution of a past serious crime against a person. The public interest in ensuring that serious crimes are solved and innocent people are not wrongly punished is likely to require disclosure even in cases where there is no fear of future repetition.

8.4 Public health

Public health doctors may need to disclose information about an individual in order to identify the source of an infection or other possible carriers. Statutory requirements for notification in such cases may not cover all of the measures necessary to protect public health but the public health doctor may decide that disclosure is justified to prevent a serious threat to other people or to protect public safety. In some cases no particular individual is perceived to be at risk from non-disclosure but there may be a generalised threat. This can be sufficient justification for disclosure if there are real grounds to suppose that harm may come if the information is not revealed. Where there are threats to particular individuals, it is often impossible to take action to protect those individuals without revealing confidential information. For example, contact tracing in meningitis involves ensuring that close (household and kissing) contacts are identified and offered antibiotic prophylaxis or vaccination as appropriate. This

activity necessarily involves revealing the diagnosis and usually the identity of the ill person too. The identities of the people to contact will usually come from the patient and the purpose of seeking these should be explained. However, if the names come from elsewhere, or the patient refuses to permit disclosure to contacts, a decision will have to be made based on the principles of avoiding serious harm discussed in section 8.2.

In other cases, there may be advantages in releasing information about a lack of risk, in order to reassure and avoid unnecessary prophylaxis. If a school child has meningitis, it is common practice for public health doctors to write, in cooperation with the school, to the parents of children in the same class or year to explain the situation. Although this would not name the ill child, he or she will usually nonetheless be identifiable. Consent from the child or the parents for this will usually be forthcoming. The purpose of the disclosure is to reassure others, to avoid telephone calls to the public health service and local doctors, and to avoid inappropriate antibiotic prescription. Thus serious harm is unlikely to occur as a result of non-disclosure, and if consent is refused, for example for fear of stigmatisation, it will not be appropriate to breach confidentiality.

8.5 Public safety

A common example of what can be categorised as public safety occurs in connection with the assessment of patients with, for example, diabetes, epilepsy, defective eyesight or serious cardiac conditions who have been advised by health professionals to discontinue driving but who nevertheless continue.⁵⁵ Where an individual has insight into the problem, it is advisable for health professionals to attempt to persuade that person to either discontinue the risky behaviour or to agree to disclosure being made to a responsible body as one step towards a change of behaviour. In some cases, the individual is unable or unwilling to follow the recommended course of action and health professionals have to weigh up the likelihood of serious harm and the need to breach confidentiality. Health professionals must consider whether non-disclosure in relation to a foreseeable and serious threat might leave them open to a possible charge of negligence if grave harm results from the non-disclosure. In such potential cases, it is advisable to consult professional, regulatory or indemnifying bodies.

Issues of public safety may similarly arise in circumstances where an individual legitimately possessing firearms is thought by health professionals to be a risk because of drug or alcohol addiction or a medical condition such as depression.⁵⁶

8.6 Safety in the workplace

Disclosure is justifiable where failure to do so in regard to the health status of an employee could foreseeably result in a substantial risk to others. For example an occupational health doctor has a responsibility to take action if he or she is aware that the health of an employee threatens the safety of others. Similarly, GPs may need to take action if they become aware that a patient they consider to be a threat to vulnerable people begins working with young children, the elderly or other vulnerable groups.

Action may be necessary if a colleague poses a threat to the health of his or her patients by reason of illness, incompetence or addiction. An example of appropriate disclosure in the public interest is found in the guidance issued by the GMC which states that:

*If you know, or have good reason to believe, that a medical colleague or a health care worker who has, or may have, a serious communicable disease, is practising, or has practised, in a way which places patients at risk, you must inform an appropriate person in the health care worker's employing authority, for example an occupational health physician, or where appropriate, the relevant regulatory body.*⁵⁷

8.7 Medical reports for fertility treatment

Most available guidance confines its concerns to the threat to existing people. However, requests for medical reports in connection with the provision of fertility treatment sometimes raise questions of doctors' duties to have regard for the wellbeing of children who might be born as a result of reproductive services. Where there is cause for concern, for example where the people seeking treatment are known to have abused children in the past, or have convictions relating to child abuse or neglect, it is essential to discuss this with the patient(s) concerned. If voluntary disclosure cannot be achieved, it may be necessary for relevant information to be disclosed to an appropriate body or individual. In such cases, it is advisable to consult professional, regulatory or indemnifying bodies.

9 Examples of disclosure in the public interest

9.1 Abuse and neglect

The need to disclose information to protect children or vulnerable adults may arise if there is suspected abuse, neglect or non-accidental injury. It is important that doctors are aware of their responsibilities in this area, since they risk criticism if they take inappropriate or premature action, or if they delay taking action where there are serious grounds for concern.

In any case where abuse is suspected, the vulnerable person's wellbeing is paramount, and the promotion of such should be the motivating factor in any decision to disclose. Wherever possible, doctors should discuss disclosure with the individual concerned and seek consent.

The situation will determine what steps doctors are able to take in making a decision to disclose information. The sections below offer advice on what steps should be considered, including:

- taking time to persuade a patient to disclose information voluntarily;
- informing the patient of the intention to disclose; and
- informing others of the intention to disclose.

However, in some circumstances disclosure will be urgently required to avert serious harm. In such cases doctors will have to weigh up the benefits of taking time to involve and inform patients and the risks associated with delaying.

Decisions about disclosure in this area are complex and must be taken with care. The family doctor may be well placed to encourage families towards a successful resolution of difficulties. The GP is often the trusted advisor, and can help families to achieve an outcome in the best interests of

individuals and the family as a whole. It is important for doctors to try to keep that position of trust and to avoid being seen in a merely policing role.

9.1.1 Where the individual lacks capacity to consent

Where the victim of abuse lacks the capacity to take decisions about disclosure, doctors must take action to protect that person's interests. The BMA considers it to be clearly in the interests of the public to identify and prevent such abuse.

The GMC offers the following advice:

"If you believe a patient to be a victim of neglect or physical or sexual abuse, and unable to give or withhold consent to disclosure, you should usually give information to an appropriate responsible person or statutory agency, in order to prevent further harm to the patient. In these and similar circumstances, you may release information without the patient's consent, but only if you consider that the patient is unable to give consent, and that the disclosure is in the patient's best medical interests".⁵⁸

Even if consent to disclosure cannot be gained, doctors should seek and encourage cooperation from their patient wherever feasible. He or she should usually be informed that the doctor intends to disclose information and should be offered counselling and support.

9.1.2 Where the patient has the capacity to consent

Exceptionally difficult are cases where the patient does have the capacity to take decisions about disclosure for him or herself, but refuses to permit disclosure so that action against an abuser can be taken. Ethically, it is clearly important to respect the wishes of a competent patient. An example of where this may arise is in the case of domestic violence. Women are often reluctant to share information about domestic violence and doctors have an important role to play in identifying victims and persuading women to take action to protect themselves. A BMA report on domestic violence discusses this role of health professionals, and advises doctors to respect privacy whilst trying to encourage voluntary disclosure.⁵⁹

From a practical perspective, disclosing against a competent patient's wishes is unlikely to be productive. The patient might feel betrayed and lose trust in the doctor, and could refuse to cooperate with any investigation of alleged abuse. If possible, patients should be given time to come to a firm decision about disclosure. Counselling and support in the interim may help the patient decide, and is essential throughout.

However, where one family member is being abused, there is a risk that others are too. For example, there is a high probability that if the wife and mother of a family is being abused, children will be at risk of harm, if not of actual abuse then harm caused by witnessing abuse or its effects on others.⁶⁰ Where somebody suffering abuse refuses to allow a doctor to disclose information, doctors will have to assess whether there are grounds for disclosing without consent. For example, there may be a serious crime being committed (see section 8.3) or there may be others at risk of harm from abuse or neglect. Doctors must weigh the advantages and disadvantages of disclosure versus non-

disclosure and take a decision based on the individual circumstances. Disclosure without consent will be justified in some cases.

It follows that doctors should never make promises of secrecy. The balance to be struck between maintaining the trust of the patient who reveals information about abuse, and the protection of his or her interests can be very difficult. Counselling and support throughout is essential, with the doctor explaining why confidentiality might be breached in a given situation.

Doctors may find it helpful to discuss cases, anonymously, with professional or indemnifying bodies.

9.1.3 Information about third parties

Disclosure in order to prevent abuse may involve the identification of alleged abusers, and may include information which the doctor learnt in his or her professional capacity as their doctor. It is clear that legally and ethically the interests of the child or vulnerable adult are paramount, and in some cases this will require a doctor to breach a third party's confidentiality without consent.

However, while ensuring the safety and welfare of the child or vulnerable adult, efforts must also be made to protect the relationship of trust between the health professionals involved and others to whom they have provided health care. Published guidance in the area of child protection emphasises that whilst it is the child whose interests are paramount, doctors do have obligations to others who are their patients, and it is acknowledged that doctors may find it extremely difficult to take decisions about disclosure where alleged abusers are also their patients.⁶¹ Social workers and health professionals are required to try to work constructively with parents or other carers, giving due weight to their interests where the latter do not place the child in danger.

If it is possible to involve parents and carers in the decision to disclose information concerning possible abuse, this may be helpful in encouraging all parties to work together towards what is in the best interests of the family. A goal of child protection is to work to keep families together and promote good parenting and family relationships. The interests of family members are often interrelated and solutions should ideally involve working with all concerned. The consent or refusal of family members regarding disclosure will not always be determinative in the decision whether to disclose, and where permission is not forthcoming disclosure may still be justified. Sometimes, however, this is not only inadvisable but could proliferate the risks to victims of abuse.

Where information is to be disclosed, it is important that only that information which is necessary to achieve the objective is released. At the point of initial contact between doctor and social services, for example, it is unlikely to be necessary for the immediate purpose of preventing harm for the full medical history of family members to be revealed. At later stages of an investigation into abuse, however, such facts may be pertinent.

9.1.4 Requests for information

Examples of where a doctor may be asked to participate in revealing information to investigate abuse is where a social worker approaches the doctor requesting information, or where the doctor is asked to participate in a child protection case conference. Case conferences involve the bringing together of various agencies and individuals, possibly including the child, relatives and carers to assess the risk to the child and, if necessary, formulate a child protection plan. The GP with continuing responsibility for the child and family has a vital role to play in this process, and other doctors may also be involved.

In any case where disclosure is requested, doctors must bear in mind the issues discussed in this section, and take decisions based on the best interests of the vulnerable person. Doctors should usually discuss disclosure with the individual concerned, and seek their consent, unless to do so could be prejudicial to the interest of the vulnerable person.

If doctors are asked to reveal information to a social worker which has no apparent relevance to the issue in question, the doctor should object and try to ascertain why the information is requested. To reveal information in such a case without demonstrable justification could leave the doctor open to criticism. The fact of a request from a social worker is not necessarily sufficient justification on its own although these professionals are working towards the same goal and cooperation with them should usually be forthcoming.

If doctors are asked to reveal to a case conference information which he or she considers should not be revealed to all present, or which is not relevant to the proceedings, the doctor should make this known to the chairman of the conference and discuss whether alternatives are available. For example, it may be possible to disclose information to a limited group of conference members, or to just the chairman.

Further advice on issues of confidentiality and child protection from the BMA, Department of Health and Conference of Medical Royal Colleges can be found in *Child Protection: Medical Responsibilities* which is available from the Department of Health. Advice may also be sought from professional and indemnifying bodies.

9.2 Genetic information

The principles of confidentiality apply equally to genetic information as to other health information. With information which has a genetic component however, the results of specific tests or more generalised family histories for example, there is an added dimension of the information's direct relevance to family members. This can present health professionals with a conflict between the preservation of one person's confidentiality and a duty to protect others from avoidable harm and suffering. It is the BMA's advice that in all areas of health care, the doctor's duty of confidentiality to their patients is of fundamental importance and should only be breached for the reasons identified in this guidance. The Association also believes that individuals have moral responsibilities to their relatives, which means that they should at least consider the implications of their actions for their family, and take an informed decision about whether to share the results of genetic tests with their relatives. Health professionals have

an important role to play in advising people of the implications of test results for other family members, and in encouraging the sharing of information with those affected. In the BMA's experience, often patients will be willing to share relevant information. However, unless there are overwhelming reasons to override a decision not to inform family members, refusals to do so must be respected.

If patients cannot be persuaded to share relevant information with their relatives for whom it has implications, doctors should consider the following points:

- the severity of the disorder;
- the level of predictability of the information provided by testing;
- what, if any, action the relatives could take to protect themselves or to make informed reproductive decisions, if they were told of the risk;
- the level of harm or benefit of giving and withholding the information; and
- the reason given for refusing to share the information.⁶²

If having considered these factors the doctor feels that the balance lies in favour of making a disclosure against a patient's wishes, he or she must discuss this with the patient before disclosing the information, and must explain the reasons why this is considered to be justified. Wherever possible in such cases it is advisable for information to be passed to family members in a way that does not identify the patient, for example by saying that information has been gained from "a relative" without naming him or her.

Whether information is to be shared with relatives with or without consent, the process of sharing must be approached with sensitivity to protect family members' rights not to know. Information should not be forced upon an unwilling recipient. The BMA offers further advice and guidance on this and other issues relating to genetics in its book *Human Genetics: Choice and Responsibility*.⁶³

10 Safeguards

10.1 Legislation

The BMA believes that the best way to ensure adherence to standards of confidentiality and clarification of the authority to breach confidentiality in the public interest is legislation. Legislation to encompass the principles and discretion to disclose outlined in this guidance would provide patients, health professionals and other health care workers with means for redress where confidentiality was breached, and protection where they acted in good faith. The 1996 Collection, Use and Disclosure of Personal Health Information Bill drafted by the BMA and other bodies representative of health professionals would have satisfied this requirement.

10.2 Public debate

Accompanying such statute there should be wide public debate about the issues raised in this document and also about how changes in the provision of health care in Britain are affecting the traditional duty of confidentiality owed by health professionals.

10.3 A national body

The BMA supports the introduction of a national body on confidentiality, which should:

- Have powers to police and inspect, to ensure standards are being met;
- Audit, in its true sense of monitoring how standards are being met, identify reasons why if they are not being met and ensure implementation of changes in practice to meet those standards;
- Regulate and monitor the use of patient identifiable information (on an individual and broader basis, for example information held in large databases);
- Ensure that training in the ethical and legal issues around confidentiality is provided for non-clinicians in the health service;
- Advise on security issues, including, for example, how information should be protected from direct access or browsing by anyone who is not treating the patient to whom the information relates; and
- Oversee training in the use of IT within the health service.

10.4 Clarification of responsibilities

In the BMA's view, a fundamental safeguard is provided if all disclosures in the absence of consent from the subject or that person's representative are made by or in conjunction with a qualified health professional. This means not only that those making difficult decisions about disclosure have clear professional ethical codes to support them but also that individuals who consider an inappropriate disclosure has been made have additional means of redress besides the courts and other complaints procedures. Qualified health professionals can be called to account by their regulatory bodies and can be removed from their register if they have disclosed information without proper justification.

Patient records can contain information recorded by different professionals such as doctors, dentists, nurses and pharmacists. Levels of responsibility and arrangements for delegating decision-making will vary between professionals and according to local practice. However, each responsible qualified health professional, as an autonomous practitioner, will be accountable for his or her own actions. Wherever it is possible, the health professional who has overall responsibility for the management of care should be consulted before making a disclosure without consent in the public interest. In the case of in-patient care, this would be the consultant. Clearly if to do so would cause unacceptable delay, decisions will have to be taken by others. Advice can always be sought from professional or indemnifying bodies.

10.5 Management arrangements

Health service bodies have responsibilities with regard to the protection of information held by the body including:

- to make arrangements to ensure that information is securely stored and not misused;
- to take steps to ensure that disclosures are made only to those who need the information and that those to whom the disclosure is made are aware of the responsibility for continued confidentiality which they assume and have themselves suitable mechanisms to uphold that responsibility;
- to ensure that the body's employees, independent contractors, volunteer helpers, students and observers of health care procedures are subject to contractual obligations of confidentiality, are aware of these obligations and have received information and/or

training on the issues and are aware of the penalties for breaching confidentiality; and

- to collect statistics relating to the number and nature of non-consensual disclosures for audit purposes.

10.6 Procedures in cases of complaints

Where any person has made a complaint to a health service body that information collected or held by the health service body has been disclosed inappropriately, in the BMA's view the matter must be investigated and a written report provided for the patient or the patient's representative. This report should record the facts of the investigation and specify what action the body proposes to take, or has taken, in the matter. Complaints can also be made to the Health Service Ombudsman.

When a complaint, investigation or disciplinary process is being considered, it may be necessary to disclose personal health information relevant to that process. Nevertheless, the individuals whose information is needed for the investigation should be asked in advance to consent to disclosure. When people are unable to consent to disclosure themselves, essential information can be disclosed to a solicitor acting on behalf of an injured patient in complaint or negligence proceedings. Only information which is essential for the purpose should be disclosed and thought must be given to the options for anonymising the information if the subject has objections to its use. In some circumstances, however, the public interest in maintaining standards and protecting other patients will dictate disclosure of identifiable health information without the individual's consent, or after an individual's death.

Contact information

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Department of Health, Wellington House, 133-155 Waterloo Road, London SE1 8UG. Tel: 020 7972 2000, Website: www.open.gov.uk/doh/dhhome.htm

General Medical Council, 178-202 Great Portland Street, London W1N 6JE. Tel: 020 7580 7642, Fax: 020 7972 4196, Website: www.gmc-uk.org

Lord Chancellor's Department, Selborne House, 54-60 Victoria Street, London SW1E 6QW. Tel: 020 7210 8500, Website: www.open.gov.uk/lcd/lcdhome.htm

Medical Defence Union, 3 Devonshire Place, London W1N 2EA. Tel: 020 7486 6181, Fax: 020 7935 5503, Website: www.the-mdu.com

Medical and Dental Defence Union of Scotland, Mackintosh House, 120 Blythswood Street, Glasgow G2 4EA.

Tel: 0141 221 5858, Fax: 0141 228 1208, Website: www.mddus.com

Medical Protection Society, 33 Cavendish Square, London W1M 0PS. Tel: 020 7399 1300, Fax: 020 7399 1301, Website: www.mps.org.uk/medical/

Public Concern at Work, Suite 306, 16 Baldwins Gardens, London EC1N 7RJ. Tel: 020 7404 6609, Fax: 020 7404 6576, Website: www.pcaw.demon.co.uk

Royal College of Nursing, 20 Cavendish Square, London W1M 0AB. Tel: 020 7409 3333, Fax: 020 7647 3435, Website: www.rcn.org.uk

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC), 23 Portland Place, London W1N 4JT. Tel: 020 7637 7181, Fax: 020 7436 2924, Website: www.ukcc.org.uk

Bibliography of relevant BMA publications – updated 2006

Advance Statements About Medical Treatment (BMA, 1995) withdrawn – under revision

This code of practice for health professionals was prepared by a multi-professional group and reflects good clinical practice in encouraging dialogue about individuals' wishes concerning their future treatment. It has a broad practical approach, considers a range of advance statements, advises of dangers and benefits of making treatment decisions in advance and combines an annotated code of practice with a quick pull out guide for easy reference. [£4.95 members, £5.95 non-members]

Assessment of Mental Capacity (2nd edition, 2004) ISBN 0 7279 1671 8

This book has been drawn up jointly by the British Medical Association and the Law Society and will prove an invaluable guide for health and legal professionals, carers and all those involved in looking after people with suspected mental impairment. The second edition of this popular book has been updated to take account of changes in the law and professional guidance including: legal changes since 1995; changes in civil litigation and other court procedures; new chapter on key professional and ethical issues in both medical and legal practice; recent government and professional guidance on related matters and proposals for law reform. [£18.95 members, £19.95 non-members]

Changing Conceptions of Motherhood - The Practice of Surrogacy in Britain (BMA, 1996) ISBN 0 7279 1006 X

Developments in reproductive technology have opened up new opportunities for those unable to have children in the usual way. But with these developments come new ethical and legal dilemmas. This book aims to equip health professionals with the necessary information to help inform these decisions by bringing together information on the medical, legal, ethical, psychological and practical aspects of surrogacy. It also aims to inform the interested reader about the practice of surrogacy in Britain. [£5.95 members, £6.95 non-members]

Human Genetics: Choice and Responsibility (Oxford Paperbacks, OUP, 1998) ISBN 0 19 288055 1

This is an authoritative and up-to-date assessment of the ethical issues raised by human genetics. The BMA, drawing on the expertise of a wide range of advisers, has produced a compact and accessible report on a subject of increasing public concern. The report confronts the often conflicting demands of choice and responsibility, opening up the debate about who will control the power unleashed by genetic research, and suggesting practical solutions for doctors, counsellors, patients, and policy makers. [£7.99 members and non-members]

Medical Ethics Today (2nd edition, 2004) ISBN 0 7279 1744 7

Medical Ethics Today (MET) is recognised as a standard textbook for health professionals and medical students. Its comprehensive coverage of the principles and practice of clinical ethics has established it as a first-line reference. Now the second edition has doubled in length, with more topics including the use of chaperones, handling requests for assisted suicide and paternity testing; new issues including ethics in public health, education and training, accident and emergency practice and after a patient's death; summaries of legal cases, lists of statutes and case law, illustrative case histories. Complete with fully searchable CD ROM, this is an essential book for every practice, hospital department and medical library. [£60.00 hardback and e-book view and print; £45.00 e-book print only; CD ROM £19.95]

The Older Person - Consent and Care (BMA, 1995) ISBN 0 7279 0912 6

This working document is aimed at all those caring for older people. Prepared by specialists from the BMA, Royal College of Nursing and Age Concern, it provides background information based on issues surrounding caring for older people and practical guidance that can be referred to quickly on a daily basis. It includes case studies to illustrate good practice; guidelines regarding consent and care; and general guidance about how to address gaps between the theory and reality of care. [5.95 members, 6.95 non-members]

Withholding and Withdrawing Life-Prolonging Medical Treatment: Guidance for Decision Making (Second edition 2001) ISBN 0 7279 1456 1 – 3rd edition in press

This report offers comprehensive guidance on the controversial and emotive issue of withholding and withdrawing life-prolonging treatment from patients of all ages. Produced following a wide-ranging consultation exercise, this book will be of vital importance to all in the medical profession and beyond. It addresses questions that involve patients, their families, and frequently the courts; questions to which there are often no clear answers but on which those who must take the decisions need advice. [£8.95 members, £9.95 non-members] Entire text available on BMJ website www.bmj.com/withwith/ww.htm.

Consent, Rights And Choices In Health Care For Children And Young People (2000) ISBN 0 7279 1228 3

This book offers comprehensive practical guidance on the ethical and legal issues which arise in the health care of patients under 18 years of age, reflecting the questions faced by health professionals every day - consent, refusal of treatment, confidentiality - as well as exceptional cases, e.g. where there is disagreement about whether treatment should be given, or where the treatment itself is controversial or innovative. Includes: an ethical approach to treating children and young people; the law on children, consent, and medical treatment; confidentiality; involving children and assessing a child's competence; refusal of treatment and decisions not to treat; mental health care of children and young people; sensitive or controversial procedures; research and innovative treatment; health care in schools; summary of good practice. Covers the legal position in England, Wales, Northern Ireland and Scotland. [£18.95 members, £19.95 non-members] Extracts (including summary of good practice) at www.bmj.com/consent/

Information about subjects covered by the Medical Ethics Committee may be obtained from the BMA's website at: www.bma.org.uk.

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Publications from the Ethics Department – updated 2006

Guidance from the Ethics Department (available from our website www.bma.org.uk)

- Abortion
- Access to health records
- Access to Medical Reports Act
- Adults with incapacity - medical treatment for (Scotland)
- Asylum seekers - access to health care
- Asylum seekers - examination
- Cardiopulmonary resuscitation
- Child protection – doctors' responsibilities
- Confidentiality & disclosure of health information
- Confidentiality & people under 16
- Confidentiality for police surgeons
- Consent form - BMA/Law Society of England and Wales – 2nd edition
- Consent form - BMA/Law Society of Scotland
- Considering surrogacy?
- Duty of candour?
- Ethical implications in treating doctors who are patients
- End of life decisions
- Female genital mutilation
- Firearms
- GP insurance package - BMA/ABI
- Healthcare of detainees in police stations, 2nd edition
- Impact of the Human Rights Act
- Interface between NHS & private treatment
- Incentives to GPs for referrals or prescribing
- Intimate body searches
- Law & ethics of male circumcision
- Medical information & insurance
- Parental responsibility
- Paternity testing
- Providing medical care & treatment to people who are detained
- PVS - treatment decisions
- Taking & using visual & audio images of patients
- Taking blood specimens from incapacitated drivers
- Xenotransplantation

Discussion papers (available from our website www.bma.org.uk)

- Abortion time limits - a briefing paper from the BMA
- Confidentiality as part of a bigger picture - a discussion paper
- Gene Patenting – a discussion paper
- Human “cloning” – BMA position on

- Human "cloning" - a discussion paper for the World Medical Association
- Euthanasia and physician assisted suicide: do the moral arguments differ?
- Treatment of patients in persistent vegetative state (PVS)
- Organ donation in the 21st century: time for a consolidated approach

Notes and references

1. *Our Answers: Data protection and the EU directive, 95/46/EC*, Data Protection Registrar, July 1996.
2. The draft legislation and accompanying handbook were originally drawn up by the Inter-Professional Working Group and were subsequently developed further by the multi-professional group on Medical Information and Patient Privacy.
3. *Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data*, 1995.
4. R and Department of Health (Respondent) ex parte Source Informatics Ltd (Applicant) (1999) LTL 2/6/99: TLR 14/6/99: (1999) 7 Lloyd's Rep Med 264: (1999) IT+CLR 374.
5. *Confidentiality*, MDU, 1997: 28.
6. *Medical ethics today: Its practice and philosophy*, BMA, 1993: 50-51.
7. For further guidance on this area see *Confidentiality and people under 16*, guidance issued jointly by the BMA, GMSC, HEA, Brook Advisory Centres, FPA and RCGP, 1994.
8. *Report on the review of patient-identifiable information*, Department of Health, December 1997.
9. See, for example, the BMA 1996 consultation document *Security in clinical information systems*.
10. *BMA Annual Representative Meeting*, Belfast, 1999.
11. See for example *Guidelines for doctors on the Access to Health Records Act 1990*, BMA, 1991; and *Guidelines on the Access to Medical Reports Act 1988*, BMA, 1988.
12. *Confidentiality of medical records*, DHSS, FPCL 80/88.
13. Discussed further in *Guidelines for doctors on the Access to Health Records Act 1990*, BMA, 1991.
14. *The Data Protection Act: A code of practice for general medical practitioners*, BMA General Medical Services Committee, March 1991.
15. *BMA Annual Representative Meeting*, Belfast, 1999.
16. See *Health care law*, Montgomery J, OUP, 1997: 255.
17. Account should be taken, however, of any legal issues around the use of anonymous information if consent has not been given. See section 1.4.
18. *The Data Protection Act: A code of practice for general medical practitioners*, BMA General Medical Services Committee, March 1991. The requirement for adequacy and relevance in the 1998 Act replicates that of the 1984 Act.
19. The scope of the public interest has been discussed generally in a number of legal cases such as *AG v Guardian Newspapers* [1990] 1 AC 139 (the *Spycatcher* case); *W v Egdell* [1990] 1 All ER 835; *Hellewell v Chief Constable of Derbyshire* [1995] 1 WLR 806.
20. *Confidentiality*, GMC, October 1995.
21. *Guidelines for professional practice*, UKCC, 1996.
22. See the Human Fertilisation and Embryology Act 1990 as amended by the Human Fertilisation and Embryology (Disclosure of Information) Act 1992.
23. National Health Service (Venereal Diseases) Regulations 1974.
24. Not all parents have parental responsibility. Legally both parents will have parental responsibility if they were married at the time of the child's conception, or birth, or at some time after the child's birth. Neither parent loses parental responsibility when they divorce. If the parents have never married, only the mother automatically has parental responsibility but the father may acquire that status by a parental responsibility order, agreed with the mother, or by the authority of a Court. (The government has announced its intention to amend these rules, following a consultation exercise carried out in 1998 by the Lord Chancellor's Department, so that parental responsibility is automatically conferred on unmarried fathers whose names appear on their child's birth certificate; this would require a change in legislation and it has not been established when these changes will take place.) People other than the parents may also acquire parental responsibility by the appointment of a guardian or on the order of a Court. Parents who do not have parental responsibility lack the legal authority to give consent but play an essential role in determining best interests and in the decision-making process.
For further information on parental responsibility see the Department of Health's *Introduction to the Children Act 1989*, HMSO, 1989.
25. For further guidance on this area see *Confidentiality and people under 16*, BMA, GMSC, HEA, Brook Advisory Centres, FPA and RCGP, 1994; and *Guidelines for doctors on the Access to Health Records Act 1990*, BMA, 1991.
26. *Guidelines for doctors on the Access to Health Records Act 1990*, BMA, 1991.
27. *Confidentiality*, GMC, October 1995: paras 13-14.
28. *Assessment of mental capacity: Guidance for doctors and lawyers*, BMA & The Law Society, 1995.
29. This functional test of capacity was the subject of widespread support amongst respondents to the Lord Chancellor's Department's 1998 Green Paper *Who decides? Making decisions on behalf of mentally incapacitated adults*, and is likely to feature in forthcoming legislation on the position of mentally incapacitated people and their carers. Lord Chancellor's Department Press Notice, 13 July 1999.
30. Further advice, including a chapter on the practical aspects of the assessment of capacity, is given in *Assessment of mental capacity: Guidance for doctors and lawyers*, BMA & The Law Society, 1995.
31. Access to Health Records Act 1990, s(3)1.
32. Mental Health Act 1983, s24(3) & (4).
33. *Ann Nicholson v Halton General Hospital NHS Trust* (1999) CA, 24 June 1999.
34. Two European Court of Human Rights judgments have ruled that the discharge of personnel from the UK armed forces solely on grounds of their homosexuality contravenes Article 8 of The 1950 European Convention for the Protection of Human Rights and Fundamental Freedoms. *Lustig-Prean and Beckett v The United Kingdom*, Judgment of 27 September 1999 (Nos. 31417/96 and 32377/96); *Smith and Grady v The United Kingdom*, Judgment of 27 September 1999 (Nos. 33985/96 and 33986/96). At the time of writing, however, no changes to the regulations had been made.
35. *Revised interim guidelines on confidentiality for police surgeons in England, Wales and Northern Ireland*, BMA & Association of Police Surgeons, 1998.
36. Quasi-law is discussed in *Health care law*, Montgomery J, OUP, 1997, Chapter 1. See also *Quasi-legislation: Recent developments in secondary legislation*, Ganz G, Sweet and Maxwell, 1987.
37. *Local research ethics committees*, HSG (91) 5; *Ethics committee review of multi-centre research*, HSG (97) 23.

38. *Preservation, retention, and destruction of GP general medical services records relating to patients*, HSC 1998/217.
39. *Use of personal medical records for research purposes*, Wald N, Law M, Meade T, Miller G, Alberman E, Dickinson J, *BMJ* 1994 309: 1422-4.
40. *Bolam v Friern Barnet NHC* [1957] 2 All ER 118, 1 WLR 582.
41. *Reporting adverse drug reactions*, BMA, 1996.
42. The published documents of many professional bodies are included in *Manual for research ethics committees*, Centre of Medical Law and Ethics, King's College, London.
43. *Local research ethics committees*, HSG (91) 5; *Ethics committee review of multi-centre research*, HSG (97) 23. These documents are under review. Additional guidance on the constitution of committee is given in *Standard operating procedures for local research ethics committees - comments and examples*, Bendall C, McKenna & Co, April 1994; *Guidelines on the practice of ethics committees in medical research involving human subjects*, Royal College of Physicians of London, August 1996.
44. *Good medical practice*, GMC, July 1998: para 53.
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46. *Work observation guidelines*, BMA, February 1999.
47. *Human genetics: Choice and responsibility*, Oxford University Press, 1998: 142-6.
48. *Access to general practitioners' records for financial audit*, GMC, November 1997.
49. *Post-payment verification* published in M11, 22 May 1998, available from the BMA's General Practitioners Committee Secretariat.
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52. The charity Public Concern at Work offers advice to individuals.
53. *Serious communicable diseases*, GMC, October 1997: para 22.
54. Police and Criminal Evidence Act 1985 (s 116).
55. *Confidentiality*, GMC, October 1997: para 19 and appendix I.
56. *Interim firearms guidance note*, BMA, 1996.
57. *Serious communicable diseases*, GMC, October 1997: para 35.
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62. Taken from the BMA's publication *Human genetics: Choice and responsibility*, BMA, OUP, 1998: 72.
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