#### Eleanor Cross Healthcare

#### **Confidentiality Code of Practice**

#### **Document Control**

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#### Introduction

GP Practices hold information about patients which must be kept private and confidential.

In some instances patient records can be very sensitive and may contain information concerning third parties. Patient information must not be given to others unless the patient consents or the disclosure can be justified

Mark Barrowclough is the Practice's Caldicott Guardian.

When he is satisfied that information should be released, the Practice should act promptly to disclose all relevant information. This is often essential to the best interests of the patient, or to safeguard the well-being of others

This Code of Practice outlines how the Caldicott Guardian and all Practice staff will deal with information about its Patients.

#### Patients' right to confidentiality

#### Principles

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

If you are asked to provide information about patients you must:

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

You must always be prepared to justify your decisions in accordance with this guidance

This document sets out the standards outlined that are expected of doctors when they hold or share information about patients in the revised version of the GMC document "*Raising and acting on concerns about patient safety*", effective 12 March 2012, a copy of which can be downloaded here: <u>http://www.gmc-uk.org/Raising and acting on concerns about patient safety FINAL.pdf 47223556.pdf</u>

Additional advice on how the guidance in this booklet should be put into Practice, and on the law relating to the use and disclosure of information about patients, is available in the <u>Frequently Asked</u> <u>Questions</u> Section at the end of this document.

#### **Protecting information**

When you are responsible for personal information about patients you must make sure that it is effectively protected against improper disclosure at all times

Many improper disclosures are unintentional. You should not discuss patients where you can be overheard or leave patients' records, either on paper or on screen, where they can be seen by other patients, unauthorised health care staff or the public. You should take all reasonable steps to ensure that your consultations with patients are private.

#### **Sharing information with patients**

Patients have a right to information about the health care services available to them, presented in a way that is easy to follow, understand and use

Patients also have a right to information about any condition or disease from which they are suffering. This should be presented in a manner easy to follow, understand and use, and include information about:

- Diagnosis;
- Prognosis;
- Treatment options;
- Outcomes of treatment;
- Common and / or serious side-effects of treatment;
- Likely time-scale of treatments; and
- Costs where relevant.

You must always give patients basic information about treatment you propose to provide, but you should respect the wishes of any patient who asks you not to give them detailed information. This places a considerable onus upon health professionals, yet, without such information, patients cannot make proper choices as partners in the health care process

You should tell patients how information about them may be used to protect public health, to undertake research and audit, to teach or train clinical staff and students and to plan and organise health care services. See Section <u>"Disclosing Information for Clinical Audit"</u> for further information.

#### **Disclosing information about patients**

You must respect patients' confidentiality.

Seeking patients' consent to disclosure of information is part of good communication between doctors, Practice staff and patients. When asked to provide information you must follow the guidance in this document.

#### Sharing information within the health care team or with others providing care

#### Circumstances where patients may give implied consent to disclosure

Most people understand and accept that information must be shared within health care teams in order to provide their care.

You should make sure that patients are aware that personal information about them will be shared within the health care team, unless they object, and of the reasons for this.

It is particularly important to check that patients understand what will be disclosed if you need to share identifiable information with anyone employed by another organisation or agency who is contributing to their care.

You must respect the wishes of any patient who objects to particular information being shared with others providing care, except where this would put others at risk of death or serious harm

You must make sure that anyone to whom you disclose personal information understands that it is given to them in confidence, which they must respect. All staff members receiving personal information in order to provide or support care are bound by a legal duty of confidence, whether or not they have contractual or professional obligations to protect confidentiality

Circumstances may arise where a patient cannot be informed about the sharing of information, for example because of a medical emergency. In these cases you must pass relevant information promptly to those providing the patient's care

#### **Disclosing information for clinical audit**

Clinical audit is essential to the provision of good care. All doctors in clinical Practice have a duty to participate in clinical audit.

Where an audit is to be undertaken by the team which provided care, or those working to support them, such as clinical audit staff, you may disclose identifiable information, provided you are satisfied that patients:

- Have been informed that their data may be disclosed for clinical audit, and their right to object to the disclosure; and
- Have not objected.

If a patient does object, you should explain why information is needed and how this may benefit their care. If it is not possible to provide safe care without disclosing information for audit, you should explain this to the patient and the options open to them.

Where clinical audit is to be undertaken by another organisation, information should be anonymised wherever that is practicable. In any case, where it is not practicable to anonymise data, or anonymised data will not fulfil the requirements of the audit, express consent must be obtained before identifiable data is disclosed

#### Disclosures where express consent must be sought

Express consent is usually needed before the disclosure of identifiable information for purposes such as research, epidemiology, financial audit or administration.

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

If the patient withholds consent, or consent cannot be obtained, disclosures may be made only where they are required by law or can be justified in the public interest. Where the purpose is covered by a regulation made under section 60 of the Health and Social Care Act 2001, disclosures may also be made without patients' consent.

You should make a record of the patient's decision, and whether and why you have disclosed information

Where doctors have contractual obligations to third parties, such as companies or organisations, they must obtain patients' consent before undertaking any examination or writing a report for that organisation. Doctors should offer to show patients the report, or give them copies, whether or not this is required by law.

#### Disclosure in connection with judicial or other statutory proceedings

#### Disclosures required by law

You must disclose information to satisfy a specific statutory requirement, such as notification of a known or suspected communicable disease. You should inform patients about such disclosures, wherever that is practicable, but their consent is not required

#### Disclosures to courts or in connection with litigation

You must also disclose information if ordered to do so by a judge or presiding officer of a court. You should object to the judge or the presiding officer if attempts are made to compel you to disclose what appear to you to be irrelevant matters, for example matters relating to relatives or partners of the patient, who are not parties to the proceedings

You must not disclose personal information to a third party such as a solicitor, police officer or officer of a court without the patient's express consent, except in the circumstances described below.

#### Disclosures to statutory regulatory bodies

Patient records or other patient information may be needed by a statutory regulatory body for investigation into a health professional's fitness to Practice. If you are referring concerns about a health professional to a regulatory body, you must seek the patient's consent before disclosing identifiable information, wherever that is practicable.

Where patients withhold consent or it is not practicable to seek their consent, you should contact the GMC, or other appropriate regulatory body, which will advise you on whether the disclosure of

identifiable information would be justified in the public interest or for the protection of other patients.

Wherever practicable you should discuss this with the patient. There may be exceptional cases where, even though the patient objects, disclosure is justified.

#### The public interest

#### Disclosures in the public interest

Personal information may be disclosed in the public interest, without the patient's consent, and in exceptional cases where patients have withheld consent, where the benefits to an individual or to society of the disclosure outweigh the public and the patient's interest in keeping the information confidential.

In all cases where you consider disclosing information without consent from the patient, you must weigh the possible harm (both to the patient, and the overall trust between doctors and patients) against the benefits which are likely to arise from the release of information

Before considering whether a disclosure of personal information 'in the public interest' would be justified, you must be satisfied that identifiable data are necessary for the purpose, or that it is not practicable to anonymise the data.

In such cases you should still try to seek patients' consent, unless it is not practicable to do so, for example because:

- The patients are not competent to give consent; or
- The records are of such age and / or number that reasonable efforts to trace patients are unlikely to be successful; or
- The patient has been, or may be violent; or obtaining consent would undermine the purpose of the disclosure (e.g. Disclosures in relation to crime); or
- Action must be taken quickly (for example in the detection or control of outbreaks of some communicable diseases) and there is insufficient time to contact patients

In cases where there is a serious risk to the patient or others, disclosures may be justified even where patients have been asked to agree to a disclosure, but have withheld consent.

You should inform patients that a disclosure will be made, wherever it is practicable to do so. You must document in the patient's record any steps you have taken to seek or obtain consent and your reasons for disclosing information without consent

Ultimately, the 'public interest' can be determined only by the courts; but the GMC may also require you to justify your actions if a complaint is made about the disclosure of identifiable information without a patient's consent.

The potential benefits and harms of disclosures made without consent are also considered by the Patient Information Advisory Group in considering applications for Regulations under the Health and Social Care Act 2001.

Disclosures of data covered by a Regulation 4 are not in breach of the common law duty of confidentiality.

#### Disclosures to protect the patient or others

Disclosure of personal information without consent may be justified in the public interest where failure to do so may expose the patient or others to risk of death or serious harm.

Where the patient or others are exposed to a risk so serious that it outweighs the patient's privacy interest, you should seek consent to disclosure where practicable. If it is not practicable to seek consent, you should disclose information promptly to an appropriate person or authority.

You should generally inform the patient before disclosing the information. If you seek consent and the patient withholds it you should consider the reasons for this, if any are provided by the patient.

If you remain of the view that disclosure is necessary to protect a third party from death or serious harm, you should disclose information promptly to an appropriate person or authority. Such situations arise, for example, where a disclosure may assist in the prevention, detection or prosecution of a serious crime, especially crimes against the person, such as abuse of children

#### Children and other patients who may lack competence to give consent

## Disclosures in relation to the treatment sought by children or others who lack capacity to give consent

Problems may arise if you consider that a patient lacks capacity to give consent to treatment or disclosure.

If such patients ask you not to disclose information about their condition or treatment to a third party, you should try to persuade them to allow an appropriate person to be involved in the consultation.

If they refuse and you are convinced that it is essential, in their medical interests, you may disclose relevant information to an appropriate person or authority. In such cases you should tell the patient before disclosing any information, and where appropriate, seek and carefully consider the views of an advocate or carer. You should document in the patient's record your discussions with the patient and the reasons for deciding to disclose information

#### Disclosures where a patient may be a victim of neglect or abuse

If you believe a patient to be a victim of neglect or physical, sexual or emotional abuse and that the patient cannot give or withhold consent to disclosure, you must give information promptly to an appropriate responsible person or statutory agency, where you believe that the disclosure is in the patient's best interests.

If, for any reason, you believe that disclosure of information is not in the best interests of an abused or neglected patient, you should discuss the issues with an experienced colleague. If you decide not to disclose information, you must be prepared to justify your decision

#### <u>Glossary</u>

This defines the terms used within this document. These definitions have no wider or legal significance.

Anonymised data	Data from which the patient cannot be identified by the recipient of the information. The name, address, and full post code must be removed together with any other information which, in conjunction with other data held by or disclosed to the recipient, could identify the patient. Unique numbers may be included only if recipients of the data do not have access to the 'key' to trace the identity of the patient	
Clinical Audit	Evaluation of clinical performance against standards or through comparative analysis, to inform the management of services. Studies that aim to derive, scientifically confirm and publish generalizable knowledge constitute research and are not encompassed within the definition of clinical audit in this document	
Consent	Agreement to an action based on knowledge of what the action involves and its likely consequences	
Express consent	Consent which is expressed orally or in writing (except where patients cannot write or speak, when other forms of communication may be sufficient)	
Identifiable data	Data from which a patient can be identified. Name, address and full postcode will identify patients; combinations of data may also do so, even where name and address are not included	
Implied consent	Agreement to disclosure where patients have been informed about the information to be disclosed, the purpose of the disclosure, and that they have a right to object to the disclosure, but have not done so	
Health care team	The health care team comprises the people providing clinical services for each patient and the administrative staff who directly support those services	
Patients	Used throughout the guidance to mean competent patients. Parents of, or those with parental responsibility for, children who lack maturity to make decisions for themselves, are generally entitled to make decisions about disclosures on behalf of their children	
Personal information	Information about people which doctors learn in a professional capacity and from which individuals can be identified	
Public interest	The interests of the community as a whole, or a group within the community or individuals	

#### **Frequently Asked Questions**

#### Questions relating to guidance on protecting information

(paragraphs 4–5 of Confidentiality: Protecting and Providing Information 2004)

#### Q1 What are my responsibilities for protecting information held on computers?

You must be satisfied that there are appropriate arrangements for the security of personal information when it is stored, sent or received by fax, computer, e-mail or other electronic means

If necessary, you should take appropriate authoritative professional advice on how to keep information secure before connecting to a network. You should record the fact that you have taken such advice

#### Q2 Can I send information by fax and e-mail?

Yes, you can. When information is sent between individuals or organisations, whether on paper or electronically, there is always some risk that information will be disclosed inadvertently.

You must therefore take reasonable steps to ensure that information is transmitted and received securely. For example, you must make sure your own fax machines and computer terminals are in secure areas. If it is practicable, check that the fax machine you are sending to is in a secure area too

E-mail sent by internet can be intercepted. Anonymise or encrypt data where that is practicable. If it is not practicable, consider whether the benefits of electronic transmission warrant sending identifiable data in a way which cannot be secured

## <u>Questions relating to guidance on sharing information in the health care team or</u> to others providing care

(paragraphs 10–12 of Confidentiality: Protecting and Providing Information 2004)

## Q3 Sometimes administrative staff in my GP Practice need access to patients' records. At present they can call up the whole record on screen. Is that all right?

The principles set out in paragraph 1 of Confidentiality: Protecting and Providing Information (2004) make clear that disclosures should always be kept to the minimum necessary.

When using computerised records, make sure that administrative data, such as names and addresses, can be accessed separately from clinical information, so that sensitive data is not automatically displayed. This will also help to reduce the risk of accidental breaches of confidentiality in reception areas or other areas to which patients have access

Administrative staff form part of the team which supports the provision of care, so sensitive information may be shared with them without express consent from patients. But you should make sure that patients are given information about who is in the health care team, why they may need access to information about them, and the protections in place against improper disclosures. This information can be provided in leaflets, or face to face, when new patients join a Practice

All staff who have access to clinical information must understand their duty of confidentiality, and their responsibilities. Make sure new staff receive proper training.

## Q4 Do I need consent before passing information to social services departments for the provision of care?

Where information is needed for the provision of care, you should tell patients about the proposed disclosure and about their right to object. You should explain to patients if withholding information may compromise the care they receive, but you should respect the patients' wishes.

In Scotland, in line with advice from the Scottish Executive, you should obtain express consent before passing on information to social services.

Information may be disclosed without consent, or where a patient has withheld consent, if there is an overriding public interest in the disclosure, for example, where the safety of child is in question (see also paragraphs 27–28 of Confidentiality: Protecting and Providing Information 2004).

#### <u>Questions relating to guidance on disclosing information where consent is</u> <u>needed</u>

(paragraphs 16–17 of Confidentiality: Protecting and Providing Information 2004)

#### Q5 When can information be disclosed to disease registers?

National and regional NHS disease registers are vital components of our public health programme, and provide data necessary for planning services, monitoring public health, research and the care of individuals.

It is best practice to seek consent to any disclosure, but the GMC believes that registers of this kind serve the public interest and that disclosing information to registers is not improper, where patients have been informed about disclosures and reasonable steps have been taken to act on any objections they raise

Patients must be informed at the earliest opportunity, in writing, or face to face, if identifiable information about them will be passed to registers. They must also be informed of the nature of the information to be disclosed, who will receive the information and the purpose of the disclosure.

If patients object to the disclosure, you must comply with their wishes if it is possible to do so. If it is not possible, you must explain the reasons for this to the patient and the options open to them. You must keep a record of such discussions and their outcome

Where this guidance has been followed, information to these registers will not be regarded as improper by the GMC

In England and Wales, Section 60 of the Health and Social Care Act 2001 provides for Regulations to be made to allow disclosure of information for specified purposes that have been approved by an independent statutory body, the Patient Information Advisory Group.

This provides a secure basis in law for disclosures where it is not practicable to obtain patients' consent.

Regulations have been passed enabling disclosure of data to cancer registries and to some other national databases.

## Q6 Are databases within trusts and research organisations covered by the same guidance as national or regional databases.

If you are considering setting up, or contributing to local registers, you should consider their purpose and objectives and whether you will need research ethics committee approval for the collection or review of data

You should always:

- Use anonymised data wherever this will serve the purpose
- Inform patients about how information about them will be used
- Seek patients' consent for use of identifiable data

If you believe that it is not practicable to seek patients' consent, (for example where a patient cannot be traced, or is unconscious) or to act on patients' decision (for example because computer systems do not allow for individual choice about disclosure), you must always seek further, impartial advice before disclosing data

In England and Wales you should seek a regulation under s60 of the Health and Social Care Act 2001. Regulations are made where, following consideration by the Patient Information Advisory Group (PIAG), it has been decided that there is a significant potential benefit from the research, and that it will not usually be practicable to seek consent from patients, or to anonymise the data. For this reason, where a Regulation has been made, you may rely on the PIAG assessment that it is not practicable to seek consent to disclosures.

In Scotland and Northern Ireland, you should discuss the issues with your Caldicott Guardian and / or seek advice from your defence organisation, professional association such as the BMA or from the GMC

## Q7 When can information be disclosed for monitoring the public health and the safety of medicines?

Professional organisations and government regulatory bodies which monitor the public health or the safety of medicines or devices rely on information from patients' records for their effectiveness in safeguarding the public health.

You must provide relevant information wherever possible, following the guidance in Q6 above

#### Q8 Can I use identifiable records for teaching?

Anonymised records will usually be sufficient for medical teaching and education. If for any reason you cannot anonymise records, you must not disclose non-anonymised data for education without the patient's implied or express consent

#### Q9 What about releasing records for financial and administrative purposes?

You should record financial or other administrative data separately from clinical information.

When asked to disclose information you should provide it in anonymised form, or obtain express consent to disclosure wherever that is not possible. However, some current systems may prevent data being anonymised, or express consent being sought or acted on

You must draw attention to systems which prevent you from following best Practice, and recommend change. Until that is achieved you should obtain implied consent, by ensuring patients are aware of disclosures made for financial, administrative and similar purposes, and of their right to object, or be satisfied that such information has been provided. You should provide further information about the nature and purpose of disclosures, if this is requested.

You should do your best to act on any objections to disclosures. However, in some cases, it may not be possible to provide care if patients object to disclosures. Where this is the case, and you are satisfied that there is no means of complying with the patient's wishes, you should explain to the patient the options open to him or her.

Additionally, in England and Wales, you can seek support for such disclosures without consent under s60 of the Health and Social Care Act 2001

## Q10 Do I still need consent to disclose information for research, if a research ethics committee has approved the project?

Express consent to the use of records in research must be obtained in all but the most exceptional circumstances.

These are likely to arise where research involves patients unable to consent, or where patients cannot be traced. In such circumstances you should follow the guidance on disclosures in the public interest set out in the answer to the question on disclosures for epidemiology studies above.

Additionally in England and Wales you may seek support for such disclosure under s60 of the Health and Social Care Act 2001, or be satisfied that those undertaking research have done so. If it is possible to inform patients about the use of the data, and respect any objections, you should do so.

#### Q11 I have some interesting case studies of patients which I would like to write up and publish. Do I need consent?

It is very difficult to anonymise case studies fully, especially if they are of interest because they deal with a rare condition, or the detailed history of a patient with mental illness. Similar problems apply to many photographs.

For this reason, you must obtain express consent from patients before publishing personal information about them as individuals in media to which the public has access, for example in journals or text books, whether or not you believe the patient can be identified.

Express consent must therefore be sought to the publication of, for example, case-histories about, or photographs of, patients.

#### Q12 What about using case studies and photographs in teaching?

You should obtain express consent, wherever that is practicable. If it is not practicable, you may use photographs and case studies in teaching and training, provided the material is not published or otherwise in the public domain

You must do your best to ensure that no patient is identifiable from such material.

**Q13 I am employed by a company to provide medical reports on people applying for life insurance. If they attend the consultation, can I assume they agree to the report being sent?** There are many circumstances in which doctors are asked to provide information to third parties, such as insurers or employers, either following an examination of a patient or from existing records.

Although the circumstances vary in which doctors with 'dual obligations' may be asked to disclose information, the following principles of good Practice generally apply. You should:

- Be satisfied that the patient has been told, at the earliest opportunity, about the purpose of the examination and / or disclosure, the extent of the information to be disclosed and the fact that relevant information cannot be concealed or withheld. You might wish to show the form to the patient before you complete it to ensure the patient understands the scope of the information requested
- Obtain, or have seen, written consent to the disclosure from the patient or a person properly authorised to act on the patient's behalf. You may, however, accept written assurances from an officer of a government department that the patient's written consent has been given
- Disclose only information relevant to the request for disclosure: accordingly, you should not usually disclose the whole record. The full record may be relevant to some benefits paid by government departments
- Include only factual information you can substantiate, presented in an unbiased manner
- The Access to Medical Reports Act 1988 entitles patients to see reports written about them before they are disclosed, in some circumstances. In all circumstances you should check whether patients wish to see their report, unless patients have clearly and specifically stated that they do not wish to do so

#### Questions relating to guidance on disclosures in the public interest 7

(paragraphs 22–27 of Confidentiality: Protecting and Providing Information 2004)

Q14 I work with sex offenders who are transferred from prison to hospital during their custodial sentence. A patient has recently been discharged, but I know he does not intend to register his new address with the police, as he is required to do by law. Should I tell the police he has been discharged?

The Sex Offenders Act 1997 requires the offender to register his name and address with the police. However, disclosures without consent are justified when a failure to disclose information may put the patient, or someone else, at risk of death or serious harm.

If you believe that the patient poses a risk to others, and you have good reason to believe that he does not intend to notify the police of his address, then disclosure of the patient's discharge would be justified

# Q15 A child in my Practice has recently been taken to hospital suffering serious injuries from abuse. His father is now being prosecuted. I've been asked to provide information about the child and her family for a Case Review. I'm the GP to the child's father and he won't give consent to the release of information, what should I do?

Case Reviews are often set up to identify why a child has been seriously harmed, to learn lessons from mistakes and to improve systems and services for children and their families. (In England and Wales such reviews are often referred to as Part 8 Reviews)

Where the overall purpose of a review can reasonably be regarded as serving to protect other children from a risk of serious harm, you should co-operate with requests for information, even where the child's family does not consent, or if it is not practicable to ask for their consent. Exceptionally, you may see a good reason not to disclose information; in such cases you should be

prepared to explain your decision to the GMC

#### Q16 A patient of mine is a doctor; I am concerned that he has a drinking problem which could affect his judgement. It has taken me a long time to get him to admit to any problems, and if I disclose the information to his employer or the GMC now he will probably deny everything and find another doctor. What should I do?

This patient has the same right to good care and to confidentiality as other patients. But, there are times when the safety of others must take precedence.

If you are concerned that his problems mean that he is an immediate danger to his own patients, you must tell his employing authority or the GMC straight away. If you think the problem is currently under control, you must encourage him to seek help locally from counselling services set up for doctors or for the public generally.

You must monitor his condition and ensure that if the position deteriorates you take immediate action to protect the patients in his care.

## Q17 A patient of mine suffers from a serious mental illness. He is often erratic and unstable. I know that he drives, although I have warned him that it is often unsafe for him to do so. He insists that his illness does not affect his judgement as a driver. Should I tell the DVLA?

The DVLA is legally responsible for deciding if a person is medically unfit to drive. The Agency needs to know when driving licence holders have a condition which may now, or in the future, affect their safety as a driver

Where patients have such conditions you should:

- Make sure that patients understand that the condition may impair their ability to drive. If a patient is incapable of understanding this advice, for example because of dementia, you should inform the DVLA immediately
- Explain to patients that they have a legal duty to inform the DVLA about the condition
- If patients refuse to accept the diagnosis or the effect of the condition on their ability to drive, you can suggest that the patients seek a second opinion, and make appropriate arrangements for the patients to do so. You should advise patients not to drive until the second opinion has been obtained

If patients continue to drive when they may not be fit to do so, you should make every reasonable effort to persuade them to stop. This may include telling their next of kin, if they agree you may do so

If you do not manage to persuade patients to stop driving, or you are given or find evidence that a patient is continuing to drive contrary to advice, you should disclose relevant medical information immediately, in confidence, to the medical adviser at the DVLA

Before giving information to the DVLA you should try to inform the patient of your decision to do so. Once the DVLA has been informed, you should also write to the patient, to confirm that a disclosure has been made

#### Questions relating to the guidance on disclosure after a patient's death

(paragraph 30 of Confidentiality: Protecting and Providing Information 2004)

#### Q18 Is it true that the duty of confidentiality continues after the patient's death?

Yes, but the extent to which information may be disclosed will depend on the circumstances. <u>Confidentiality: Protecting and Providing Information 2004</u> sets out criteria you need to consider. But there are circumstances in which you should disclose information, for example:

- To assist a Coroner, Procurator Fiscal or other similar officer with an inquest or fatal accident inquiry (<u>see also paragraph 32 of Good Medical Practice 2001</u>);
- To National Confidential Inquiries or other clinical audit or for education or research. Information should be anonymised wherever possible;
- On death certificates. You must complete death certificates honestly and fully;
- To provide information for public health surveillance. Anonymised information should be used unless identifiable data are essential for the purpose;
- Where a parent seeks information about the circumstances and causes of a child's death;
- Where a partner, close relative or friend seeks information about the circumstances of an adult's death, and you have no reason to believe that the patient would have objected to such a disclosure;
- Where a person has a right of access to records under the Access to Health Records Act 1990, that is information relating to a claim which may arise out of a patient's death, made to 'the patient's personal representative and any person who may have a claim arising out of the patient's death'.

#### Q19 Can I publish case studies about patients who have died?

You should follow the patient's wishes, if they are known to you. If not, you should consider whether publishing information which could be identified would cause distress to relatives or the patient's spouse or partner

If you are satisfied that the publication would not cause distress, and that you have no reason to think that the patient would have objected, you may use the case study or photo in published material.

You should of course do your best to ensure that the patient is not identifiable from the material you publish.

#### Q20 What about disclosing information to insurance companies after a patient has died?

If insurers seek information in order to decide whether to make a payment on a life assurance policy, you should disclose information to those lawfully entitled to deal with the person's estate – for example the executors of the person's will – but you should inform them of the possible consequences of the disclosure.

It may also be appropriate to inform those close to the deceased person about the release of this information

#### <u>Questions relating to guidance on disclosure to courts or in connection with</u> <u>litigation</u>

(paragraphs 18–19 of Confidentiality: Protecting and Providing Information 2004)

#### Q21 What does the law say?

This section sets out some key elements of the law on confidentiality. It is not intended to be a comprehensive list of relevant case law and legislation.

There is a large number of Acts that provide for some form of access to confidential records, which may include health records.

If you receive a request for information but are unsure about the legal basis for that request, you should ask for clarification from the person making the request and, if necessary, seek legal advice

In all four countries of the UK the common law requires consent for disclosure of identifiable data, unless there is a legal provision authorising or requiring disclosure of data, or there is an overriding public interest in the disclosure

Some of the key judgements in recent cases are:

#### Common law

A-G v Guardian Newspapers [1988] 3 All ER 545 A general summary of the law on confidence

W v Egdell [1990] 1 All ER 835 and X v Y [1998] 2 All ER 648 The application of the law of confidence to doctors

R v Department of Health exparte Source Informatics Ltd [2000] 1 All ER 786 The effect of anonymisation on confidentiality

#### Legislation

#### Access by patients

Two pieces of legislation give patients, or their authorised representatives, access to information about themselves:

#### Data Protection Act 1998

Rights of access for patients to their medical records Right to know about what data is used for

Advice on how the guidance applies in clinical care and in research, epidemiology etc. is available from the Office of the Information Commissioner (<u>http://www.dataprotection.gov.uk/</u>). The Data Protection Act 1998 also places a duty on those who process data to do so lawfully (in accordance with relevant legislation or case law) and fairly (keeping people informed about how their personal information is being used)

#### Access to Medical Reports Act 1988

Provides for patients to see reports written about them for insurance or education purposes by a doctor who has provided their clinical care

#### Access by others

#### Disclosure in relation to a court order

The courts, both civil and criminal, have power by virtue of the various pieces of legislation that govern their operation, to order disclosure of information. A court order will generally explain the basis on which disclosure is being ordered, so we have not listed the legislation here

#### Access to Health Records Act 1990

Access to records of deceased persons

Abortion Act 1967 and Abortion Regulations 1991 (SI 1991 No 499) Disclosure of information on abortion for purposes specified in the Regulations

#### Audit Commission Act 1998

Information required to allow the Audit Commission to carry out its functions under the Act

#### Criminal Appeal Act 1995

Information required by the Criminal Cases Review Commission to assist in the exercise of their functions

#### Health and Social Care Act 2001

Gives the Secretary of State for Health the power to make Regulations specifying information to be disclosed in the public interest, or in the interest of improving patient care, for England and Wales only

Health (Community Health and Standards) Act 2003 Gives Commission for Healthcare Audit and Inspection right of access to fulfil its statutory functions

## Human Fertilisation and Embryology Act 1990 (as amended by the Human Fertilisation (Disclosure of Information) Act 1992)

Disclosure of information to the HFEA

#### Medical Act 1983

Disclosure of information to the GMC in respect of its powers to investigate complaints

#### NHS (Venereal Diseases) Regulations 1974 (SI 1974 No 29)

Emphasises the importance of confidentiality but provides for limited sharing of information between doctors

#### Police and Criminal Evidence Act 1984

Gives power to the police to apply to a court for access to records to assist in an investigation

#### Prevention of Terrorism (Temporary Provisions) Act 1989

Requires anyone to inform the police of information about terrorist activity

#### Public Health (Control of Disease) Act 1984 and SI 1988 No 1546

Notification of specified diseases and food poisoning incidents

#### Road Traffic Act 1988

Gives powers to police to require doctors to provide information which might identify a driver alleged to have committed a traffic offence