Confidentiality: Providing and Protecting Information

GENERAL MEDICAL COUNCIL

Protecting patients, guiding doctors

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The duties of a doctor registered with the General Medical Council

Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- make the care of your patient your first concern;
- treat every patient politely and considerately;
- respect patients' dignity and privacy;
- listen to patients and respect their views;
- give patients information in a way they can understand;
- respect the rights of patients to be fully involved in decisions about their care;
- keep your professional knowledge and skills up to date;
- recognise the limits of your professional competence;
- be honest and trustworthy;
- respect and protect confidential information;
- make sure that your personal beliefs do not prejudice your patients' care;
- act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;
- avoid abusing your position as a doctor; and
- work with colleagues in the ways that best serve patients' interests.

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.

Confidentiality: Providing and Protecting Information

Being registered with the General Medical Council gives you rights and privileges. In return, you have a duty to meet the standards of competence, care and conduct set by the GMC.

Doctors hold information about patients which is private and sensitive. This information must not be given to others unless the patient consents or you can justify the disclosure. Guidance on when disclosures may be justified are discussed in this booklet.

When you are satisfied that information should be released, you 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.

Principles of confidentiality

Patients' right to confidentiality

1. Patients have a right to expect that you will not disclose any personal information which you learn during the course of your professional duties, unless they give consent. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care.

2. You must respect patients' requests not to release information to third parties, except in the circumstances described at paragraphs [34-41] of this guidance.

Obtaining consent to disclosure

3. When seeking patients' consent to disclose information you must make sure that they understand to whom it will be disclosed, what will be disclosed, the reasons for disclosure and the likely consequences.

4. In all normal circumstances you should obtain the patient's consent before sharing information with the patient's relatives or partner.

Protecting information (*paragraphs 11-13)*

5. Where you are responsible for confidential information, you must take all reasonable steps to protect it from improper disclosure.

Sharing and disclosing information (*paragraphs 14-23)*

6. Good medical practice entails sharing information with patients and colleagues. It is important to share relevant information with health care professionals involved in the care of a patient, unless the patient objects. The provision of effective and efficient healthcare services also depends on the analysis of information some of which relates to individual patients. This information should be anonymised [1]or aggregated so that individual patients cannot be identified.

7. When disclosing information, you should disclose only as much information as is necessary for the purpose.

Justifying decisions

8. If you decide to disclose information you must be prepared to explain and justify your decision.

These principles apply in all circumstances, including those discussed in this booklet.

Providing information for patients

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

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[1] A recent judgment has held that disclosure of anonymised data is a breach of the common law duty of patient confidentiality, unless the disclosure can be justified because it is in the public interest, or because patients have given their implied consent. The judgment is being appealed. [R and The Department of Health ex parte Source Informatics Ltd, 28 May 1999.]

10. Patients also have a right to information about any condition or disease from which they are suffering, again presented in a manner easy to follow and use. This includes information about prognosis, treatment options, outcomes of treatment, possible side-effects of treatment, and likely time-scale of treatments. You should 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. Our booklet *Seeking Patients' Consent: The Ethical Considerations* gives further advice on providing information to patients.

Protecting information

11. When you are responsible for information about identifiable patients you must make sure that it is effectively protected against improper disclosure at all times. You must be satisfied that there are appropriate arrangements for the security of clinical information when it is stored, sent or received by post or facsimile, or by 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. You must make sure your own facsimile machine and computer terminals are in secure areas. If you send data by facsimile or computer you should satisfy yourself, as far as is practicable, that the data cannot be seen by anyone who does not need the information.

12. Many improper disclosures are unintentional. You should not discuss patients where you can be overheard or leave patients' records where they can be seen by

other patients, unauthorised health care staff or the public. Whenever possible you should take steps to ensure that your consultations with patients are private.

Sharing information with others providing care

13. Doctors cannot treat patients safely, nor provide the continuity of care which patients have a right to expect, without knowing their medical history. Passing all the relevant information to colleagues who take over the care of patients, or who provide additional care is essential to good medical practice. In the same way, when care is provided by teams of doctors and other health care workers, it is important that information should be shared within the team.

14. Where patients have consented to treatment, their explicit consent to disclosure is not always needed before relevant information is shared within a team in order to allow that treatment to be provided. For example, explicit consent would not be needed for a general practitioner may disclose relevant information to a medical secretary who will type a referral letter, or physician may make relevant information available to a radiologist when requesting an X-ray, unless the patient objects.

15. Likewise, whenever care is shared or delegated, or when a patient is referred to another health care professional, you should give your colleagues all relevant information about the patient's health and treatment, unless the patient objects. When disclosing information you should disclose only as much information as is necessary for the purpose.

16. It may also be necessary to share information with individuals employed by outside agencies who are part of the team providing health and/or social care. Where this is the case, you should make sure that patients are aware that their

information will be passed on, unless they object, and of the reasons for this. You should also ensure that those given such information about patients are aware that it is confidential and they are therefore subject to a legal duty of confidence.

17. There will also be circumstances where a patient's consent cannot be obtained, for example because of a medical emergency, but relevant information must, in the patient's interest, be transferred between health care workers.

18. You must make sure that any member of the team to whom you disclose information understands that it is given to them in confidence, which they must respect.

Disclosures where doctors have dual responsibilities

19. Situations may arise where doctors have contractual obligations to third parties, such as companies or organisations, as well as obligations to patients. Such situations may occur, for example, when doctors:

a. Provide occupational health services or medical care for employees of a company or organisation.

b. Are employed by an organisation such as an insurance company or agency assessing claims for benefits.

c. Provide medical care for patients and are subsequently asked to provide medical reports or information for third parties about them.

d. Work as police surgeons.

e. Work in the armed forces.

f. Work in the prison service.

20. If you are asked to disclose information to a third party to whom you have contractual obligations you must:

a. Be satisfied that the patient understands the reason for disclosure, the extent of the information to be disclosed and the fact that relevant information cannot be concealed or withheld. If you are asked to examine or assess a patient on behalf of a third party, you must inform the patient, at the earliest opportunity, and always before undertaking the assessment, of the purpose of the assessment and your obligation to the third party.

b. Obtain, or have seen, written consent to the disclosure from the patient or a person properly authorised to act on the patient's behalf.

c. Disclose only information relevant to the request for disclosure: accordingly, you should not usually disclose the whole record.

d. Include only factual information you can substantiate.

e. Comply with the Access to Medical Reports Act 1988; but you should ask patients if they wish to see the report, whether or not this is required by law. The only exception would be where patients have clearly and specifically stated previously that they do not wish to see the report.

21. Disclosures without consent to employers, insurance companies, or any other third party, can be justified only when they are necessary to protect others from serious harm, or for other reasons discussed in this booklet.

Medical research, medical education and clinical audit

22. Where explicit consent has not been obtained for the use of information or samples in medical research, clinical audit or the education or professional development of doctors, information should usually be anonymised before it is used by anyone outside the team which provided the patient's care. The circumstances where such anonymisation is not required are set out in the paragraphs below.

Anonymising records for medical education, clinical audit and research[2]

23. Staff from outside the health care team are sometimes employed to anonymise records. You must be satisfied that they are properly trained and authorised by the health authority, NHS trust or comparable body to carry out this work, and are subject to a duty of confidentiality in their employment. The fact that records (including those already held by the doctor or institution) may be disclosed to persons outside the team which provided the patient's care for the purposes of anonymisation, and that patients have a right to object to such a process, must be made accessible to patients, for example, through practice or hospital leaflets, and in notices in waiting areas. This information must be made available to each patient before his or her clinical information is disclosed. The data must be used only for clinical or medical audit, for medical education or for research.

[2] The guidance which follows conforms with legal advice obtained by the GMC on the disclosure of records for the purpose of anonymisation for clinical audit, education and research. Legal advice obtained by others indicates that there is a range of opinion on how the courts would consider such disclosures. Until a case is tested in the courts the matter cannot be fully resolved.

Disclosures for clinical audit and education

24. Where it is not possible to anonymise the data you should obtain explicit consent to disclosure, where that is practicable. Where it is not practicable, you should make available to the patient, someone authorised by the patient, or where the patient has died, the personal representatives of the deceased person's estate, the information described in paragraph 23.

Disclosures for medical research

25. Where, after serious consideration, you judge that records or samples cannot be anonymised and it is not practicable to contact patients to seek their consent, this fact should be drawn to the attention of a research ethics committee which should decide whether the likely benefits of the research outweigh the loss of confidentiality . Disclosures may otherwise be improper, even if the recipients of the information are registered medical practitioners. The approval of a research ethics committee would be taken into account by a court if a claim for breach of confidentiality were made, but the court's judgement would be based on whether the public interest was served. More detailed guidance, which may be helpful in deciding when the use of records without approval is justified, is issued by other bodies, such as the Medical Research Council and the Royal College of Physicians.

Cancer and other registries

26. Information about patients may be sent to a registry for use in research, public health surveillance and planning. You should inform patients that you wish to do this, and make sure they know that they have a right to object to such

disclosures. You must respect any such objection. In such cases, you may pass on anonymised information if asked to do so.

27. Where patients express no objection, you should nonetheless take into account, before passing on the relevant information, the registry's own commitment to confidentiality and their arrangements for safeguarding the security of the information provided to them. You may also wish to consider the likely benefit to the public of the work carried out by the registry. If there is little or no evident public benefit - for example, where the registry appears to be operating for purely commercial reasons - you should not disclose information without the explicit consent of the patient.

28. The automatic transfer of information to a registry, whether by electronic or other means, prior to informing the patient that their information will be passed on, is unacceptable, save in the most exceptional circumstances. These would be where a court has already decided that there is such an overwhelming public interest in the disclosure of information to a registry that patients' rights to confidentiality are overridden; or where you are willing and able to justify the disclosure, potentially before a court or to the GMC, on the same grounds.

Publication

29. You must obtain consent from patients before publishing personal information about them as individuals in journals, text books or other media in the public domain, whether or not you believe the patient can be identified. Consent must therefore be sought to the publication of, for example, case-histories about, or photographs of, patients. Where you wish to publish information about a patient who has died, you should take into account the guidance in paragraphs [42 and 43] before deciding whether or not to do so.

Disclosures for administrative purposes including financial audit[3]

30. Where information is needed for administrative purposes, particularly where records are requested for financial audit or other administrative purposes, or are requested by an inspector of taxes, you must provide them in anonymised form, wherever anonymised records will satisfy the requirements of the auditor. You should make every effort to separate financial and clinical information when making records

31. Each patient must have had access to the following information before his or her records are used for administrative purposes including financial audit:

a. That information about them, including the records already held by the doctor or institution, might be used in confidence for the purposes of healthcare administration, including financial audit.

b. That information may be disclosed to a person outside the health care team, who has been properly trained and authorised by the Health Authority or a comparable body to carry out financial audit, or anonymisation for audit purposes, and is subject to a duty of confidentiality.

c. That the auditor may or may not be medically qualified.

d. That they have a right to object, and that such objections will be respected

[3] The guidance which follows conforms with legal advice obtained by the GMC on the disclosure of records for adminstrative purposes, including financial audit. Legal advice obtained by others indicates that there is a range of opinion on how the courts would consider such disclosures. Until a case is tested in the courts the matter cannot be fully resolved.

32. This information may be made available to patients through practice or hospital leaflets and in notices in waiting areas.

33. There may be particular concerns about the disclosure of clinical records for financial audit purposes, for example where general practitioners in NHS practice are asked to give health authority staff access to patients' records as part of the arrangements for verifying payments. It is unlikely that a refusal to allow access to information for audit would be regarded as serious professional misconduct. Equally, no question of serious professional misconduct is likely to arise where general practitioners allow access to patients' records for financial audit, provided they are satisfied that the information outlined in paragraph 31 has been made available to patients.

Disclosures without the patient's consent

Disclosure in connection with judicial or other statutory proceedings

34. You may disclose information to satisfy a specific statutory requirement, such as notification of a communicable disease.

35. You may also disclose information if ordered to do so by a judge or presiding officer of a court, or if you are summoned to assist a Coroner, Procurator Fiscal or other similar officer in connection with an inquest or comparable judicial investigation. 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 which appear in the notes, for example matters relating to relatives or partners of the patient, who are not parties to the proceedings.

36. You should not disclose information at the request of a third party such as a solicitor, police officer or officer of a court without the patient's consent, except in the circumstances described at paragraphs [38 and 39].

37. You may disclose information in response to an official request from a statutory regulatory body for any of the health care professions, where that body determines that this is necessary in the interests of justice. Wherever practicable you should discuss this with the patient. There may be exceptional cases where, even though the patient objects, disclosure is justified in the interests of patients generally.

Disclosures in the interests of others

38. Disclosures may be justified where a failure to disclose information may expose the patient or others to a risk of death or serious harm. Where third parties are exposed to such a risk, you should disclose information promptly to the appropriate person or authority:

39. Such circumstances may arise, for example:

a. Where a colleague, who is also a patient, is placing patients at risk as a result of illness or other medical condition. If you are in doubt about whether disclosure is justified you should consult an experienced colleague, or seek advice from a professional organisation. The safety of patients must come first at all times. (Our booklet *Serious Communicable Diseases* gives further guidance on this issue.)

b. Where a patient continues to drive, against medical advice, when unfit to do so. In such circumstances you should disclose relevant information to

the medical adviser of the Driver and Vehicle Licensing Agency without delay. Further guidance is given in Appendix I.

c. Where a disclosure may assist in the prevention or detection of a serious crime. Serious crimes, in this context, will put someone at risk of death or serious harm, and will usually be crimes against the person, such as abuse of children.

Disclosure in the patient's medical interests *where consent is unobtainable*

40. Problems may arise if you consider that a patient is incapable of giving consent to treatment or disclosure because of immaturity, illness or mental incapacity. If such patients ask you not to disclose information 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 must tell the patient before disclosing any information, and, where appropriate, seek and carefully consider the views of an advocate or carer. You should remember that the judgement whether patients are capable of giving or withholding consent to treatment or disclosure must be based on an assessment of their ability to appreciate what the treatment or advice being sought may involve.

41. If you believe a patient to be a victim of neglect or physical or sexual abuse and that the patient cannot give or withhold consent to disclosure, you should give information to an appropriate responsible person or statutory agency, where you believe that the disclosure is in the patient's best interests. Such circumstances may arise in relation to children, here concerns about possible abuse need to be shared

with other agencies such as social services. It will usually, but not necessarily, be appropriate for those with parental responsibility to be informed.

Disclosure after a patient's death

42. You still have an obligation to keep information confidential after a patient dies. The extent to which confidential information may be disclosed after a patient's death will depend on the circumstances. These include the nature of the information, whether that information is already public knowledge or can be anonymised, and the use to which the information will be put. For example, publishing anonymised case studies as part of confidential inquiries would be unlikely to be improper. You should also consider whether, and if so to what extent, the disclosure of information may cause distress to, or be of benefit to, the patient's partner or family.

43. Particular difficulties may arise when there is a conflict of interest between parties affected by the patient's death. For example, if an insurance company seeks information in order to decide whether to make a payment under a life assurance policy, you should not release information without the authorisation of those lawfully entitled to deal with the person's estate who have been fully informed of the consequences of disclosure. It may also be appropriate to inform those close to the patient.

If you decide to disclose confidential information you must be prepared to explain and justify your decision.

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