General
Medical
Council

Regulating doctors
Ensuring good medical practice

Confidentiality: Protecting and Providing Information (2000)

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Confidentiality: Protecting and Providing Information

GENERAL MEDICAL COUNCIL

Protecting patients, guiding doctors

Being registered with the GMC 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.

Glossary: 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. NHS numbers or other 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 using this number.
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).
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:	Competent patients and parents of, or those with parental responsibility for, children who lack maturity to make decisions for themselves. (Adult patients who lack the capacity to consent have the right to have their confidentiality respected. Guidance on disclosure of information about such patients is included in paragraphs 38-39).
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.

Section 1 - Patients' right to confidentiality

1. 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 should:

    - Seek patients' consent to disclosure of information wherever possible, whether or not you judge that patients can be identified from the disclosure.

    - Anonymise data where unidentifiable data will serve the purpose.

    - Keep disclosures to the minimum necessary.

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

Protecting information

2. When you are responsible for personal information about patients you must make sure that it is effectively protected against improper disclosure at all times[1].

3. 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. Whenever possible you should take steps to ensure that your consultations with patients are private.

1 There are particular dangers with the storage and transfer of electronic data. Further advice is at Appendix 1 of the guidance.

Section 2 - Sharing information with patients

4. 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.

5. 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 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 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.

6. It is good practice to give patients information about how anonymised information about them may be used to protect public health, to undertake research and audit, to teach or train medical staff and students and to plan and organise health care services.

Section 3 - Disclosure of information

Sharing information with others providing care

7. Where patients have consented to treatment, express consent is not usually needed before relevant personal information is shared to enable the treatment to be provided. For example, express consent would not be needed before general practitioners disclose relevant personal information so that a medical secretary can type a referral letter. Similarly, where a patient has agreed to be referred for an X-ray, physicians may make relevant information available to radiologists. Doctors cannot treat patients safely, nor provide continuity of care, without having relevant information about the patient's condition and medical history.

8. 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 it is necessary to share personal information with anyone employed by another organisation or agency providing health or social 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.

9. 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. Anyone receiving personal information in order to provide care is bound by a legal duty of confidence, whether or not that they have contractual or professional obligations to protect confidentiality.

10. 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 should pass relevant information promptly to those providing the patients' care.

Section 4 - Disclosure of information other than for treatment of the individual patient

Principles

11. Information about patients is requested for a wide variety of purposes including education, research, monitoring and epidemiology, public health surveillance, clinical audit, administration and planning. You have a duty to protect patients' privacy and respect their autonomy. When asked to provide information you should follow the guidance in paragraph 1, that is:

    - Seek patients' consent to disclosure of any information wherever possible, whether or not you judge that patients can be identified from the disclosure.
    - Anonymise data where unidentifiable data will serve the purpose.
    - Keep disclosures to the minimum necessary.

12. The paragraphs which follow deal with obtaining consent, and what to do where consent is unobtainable, or it is impracticable to seek consent.

Obtaining consent

13. Seeking patients' consent to disclosure is part of good communication between doctors and patients, and is an essential part of respect for patients' autonomy and privacy.

Consent where disclosures will have personal consequences for patients

14. You must obtain express consent where patients may be personally affected by the disclosure, for example when disclosing personal information to a patient's employer. When seeking express consent 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 can be justified in the public interest, usually where disclosure is essential to protect the patient, or someone else, from risk of death or serious harm.

Consent where the disclosure is unlikely to have personal consequences for patients

15. Disclosure of information about patients for purposes such as epidemiology, public health safety, or the administration of health services, or for use in education or training, clinical or medical audit, or research, is unlikely to have personal consequences for the patient. In these circumstances you should still obtain patients' express consent to the use of identifiable data or arrange for members of the health care team to anonymise records (see also paragraphs 16 and 18).

16. However, where information is needed for the purposes of the kind set out in paragraph 15, and you are satisfied that it is not practicable either to obtain express consent to disclosure, nor for a member of the health care team to anonymise records, data may be disclosed without express consent. Usually such disclosures will be made to allow a person outside the health care team to anonymise the records. Only where it is essential for the purpose may identifiable records be disclosed. Such disclosures must be kept to the minimum necessary for the purpose. In all such cases you must be satisfied that patients have been told, or have had access to written material informing them:

   - That their records may be disclosed to persons outside the team which provided their care.

   - Of the purpose and extent of the disclosure, for example, to produce anonymised data for use in education, administration, research or audit.

   - That the person given access to records will be subject to a duty of confidentiality.

   - That they have a right to object to such a process, and that their objection will be respected, except where the disclosure is essential to protect the patient, or someone else, from risk of death or serious harm.

17. Where you have control of personal information about patients, you must not allow anyone access to them for purposes of the kind set out in paragraph 15, unless the person has been properly trained and authorised by the health authority, NHS trust or comparable body and is subject to a duty of confidentiality in their employment, or because of their registration with a statutory regulatory body.

Disclosures in the public interest

18. In cases where you have considered all the available means of obtaining consent, but you are satisfied that it is not practicable[2] to do so, or that patients are not competent to give consent, or exceptionally, in cases where patients withhold consent, personal information may be disclosed in the public interest 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.

19. In all such cases 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.

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

Section 5 - Putting the principles into practice

21. The remainder of this booklet deals with circumstances in which doctors are most frequently asked to disclose information, and provides advice on how the principles in paragraphs 14 - 20 should be applied.

Disclosures which benefit patients indirectly

Monitoring public health and the safety of medicines and devices including disclosures to cancer and other registries

2 For example where records are of such age and/or number that reasonable efforts to trace patients are unlikely to be successful; where the patient has been or may be violent, or where action must be taken quickly for (example in the out-break of some communicable diseases) and there is insufficient time to contact patients.

22. Professional organisations and government regulatory bodies[3] which monitor the public health or the safety of medicines or devices, as well as cancer and other registries, rely on information from patients' records for their effectiveness in safeguarding the public health. For example, the effectiveness of the yellow card scheme run by the Committee on Safety of Medicines depends on information provided by clinicians. You must co-operate by providing relevant information wherever possible. The notification of some communicable diseases is required by law (see also paragraph 43), and in other cases you should provide information in anonymised form, wherever that would be sufficient.

23. Where personal information is needed, you should seek express consent before disclosing information, whenever that is practicable. For example, where patients are receiving treatment there will usually be an opportunity for a health care professional to discuss disclosure of information with them.

24. Personal information may sometimes be sought about patients with whom health care professionals are not in regular contact. Doctors should therefore make sure that patients are given information about the possible value of their data in protecting the public health in the longer-term, at the initial consultation or at another suitable occasion when they attend a surgery or clinic. Patients should be given the information set out in paragraph 16: it should be clear that they may object to disclosures at any point. You must record any objections so that patients' wishes can be respected. In such cases, you may pass on anonymised information if asked to do so.

3 Such as the Medicines Control Agency, the Committee on Safety of Medicines, the Medical Devices Agency, the Drug Safety Research Unit and the Public Health Laboratory Service.

25. Where patients have not expressed an objection, you should assess the likely benefit of the disclosure to the public and commitment to confidentiality of the organisation requesting the information. If there is little or no evident public benefit, you should not disclose information without the express consent of the patient.

26. Where it is not practicable to seek patients' consent for disclosure of personal information for these purposes, or where patients are not competent to give consent, you must consider whether disclosures would be justified in the public interest, by weighing the benefits to the public health of the disclosure against the possible detriment to the patient.

27. The automatic transfer of personal information to a registry, whether by electronic or other means, before informing the patient that 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.

Clinical audit and education

28. Anonymised data will usually be sufficient for clinical audit and for education. When anonymising records you should follow the guidance on obtaining consent in paragraphs 15-17 above. You should not disclose non-anonymised data for clinical audit or education without the patient's consent.

Administration and financial audit

29. You should record financial or other administrative data separately from clinical information, and provide it in anonymised form, wherever that is possible.

30. Decisions about the disclosure of clinical records for administrative or financial audit purposes, for example where health authority staff seek access to patients' records as part of the arrangements for verifying NHS payments, are unlikely to bring your registration into question, provided that, before allowing access to patients' records, you follow the guidance in paragraphs 15-17. Only the relevant part of the record should be made available for scrutiny.

Medical research

31. Where research projects depend on using identifiable information or samples, 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 so that it can consider 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 decision 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 its own assessment of whether the public interest was served. More detailed guidance is issued by the medical royal colleges and other bodies.

Publication of case-histories and photographs

32. 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. Where you wish to publish information about a patient who has died, you should take into account the guidance in paragraphs 40-41 before deciding whether or not to do so.*

Disclosures where doctors have dual responsibilities

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

- Provide occupational health services or medical care for employees of a company or organisation.
- Are employed by an organisation such as an insurance company.
- Work for an agency assessing claims for benefits.
- Provide medical care for patients and are subsequently asked to provide medical reports or information for third parties about them.
- Work as police surgeons.
- Work in the armed forces.
- Work in the prison service.

* X-rays and images taken from pathology slides are not covered by this guidance.

34. If you are asked to write a report about and/or examine a patient, or to disclose information from existing records for a third party to whom you have contractual obligations, you must:

- 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[4].

4 In some cases other bodies give patients access to reports, for example, the Department of Social Security gives all claimants access to reports made in connection with state benefits. In such cases it is not necessary for you to check patients' wish to see the report.

35. Disclosures without consent to employers, insurance companies, or any other third party, can be justified only in exceptional circumstances, for example, when they are necessary to protect others from risk of death or serious harm.

Disclosures to protect the patient or others

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

37. Such circumstances may arise, for example:

    - 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.)

    - 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. Fuller guidance is given in Appendix 2.

- Where a disclosure may assist in the prevention, detection or prosecution 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.

Children and other patients who may lack competence to give consent

38. 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[5]. 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[6]. 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 document in the patient's record the steps you have taken to obtain consent and the reasons for deciding to disclose information.

5 Guidance on assessing patients' capacity to make decisions is provided in our booklet *Seeking Patients' Consent: The Ethical Considerations.*

6 In some cases disclosures will be required for example under some sections of the Mental Health Act 1983, under the Adults with Incapacity (Scotland) Act 2000.

39. 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 should give information promptly to an appropriate responsible person or statutory agency, where you believe that the disclosure is in the patient's best interests. You should usually inform the patient that you intend to disclose the information before doing so. Such circumstances may arise in relation to children, where concerns about possible abuse need to be shared with other agencies such as social services. Where appropriate you should inform those with parental responsibility about the disclosure. If, for any reason, you believe that disclosure of information is not in the best interests of an abused or neglected patient, you must still be prepared to justify your decision.

Disclosure after a patient's death

40. You still have an obligation to keep personal 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 intended use to which the information will be put. You should also consider whether the disclosure of information may cause distress to, or be of benefit to, the patient's partner or family.

41. There are a number of circumstances in which you may be asked to disclose, or wish to use, information about patients who have died. For example:

   - To assist a Coroner, Procurator Fiscal or other similar officer in connection with an inquest or fatal accident inquiry. In these circumstances you should provide relevant information (see also paragraph 19 of *Good Medical Practice*).

- As part of National Confidential Enquiries or other clinical audit or for education or research. The publication of properly anonymised case studies would be unlikely to be improper in these contexts.

- On death certificates. The law requires you to complete death certificates honestly and fully.

- To obtain information relating to public health surveillance. Anonymised information should be used unless identifiable data is essential to the study.

42. 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 release information in accordance with the requirements of the Access to Health Records Act 1990 or with 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.

Section 6 - Disclosure in connection with judicial or other statutory proceedings

43. You must disclose information to satisfy a specific statutory requirement, such as notification of a known or suspected communicable disease.

44. 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.

45. You should 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 at paragraphs 36-37, 39 and 41.

46. You may disclose personal information in response to an official request from a statutory regulatory body for any of the health care professions[7], where that body determines that this is necessary in the interests of justice and for the safety 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.

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

7 For example, the General Medical Council, the General Dental Council, the United Kingdom Central Council for Nursing, Midwifery and Health Visiting, the Council for Professions Supplementary to Medicine; the General Optical Council, the General Osteopathic Council and the General Chiropractic Council.

Appendix 1

Electronic processing

1. 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.

2. 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.

3. You must make sure your own fax machine and computer terminals are in secure areas. If you send data by fax you should satisfy yourself, as far as is practicable, that the data cannot be intercepted or seen by anyone other than the intended recipient.

4. When deciding whether, and in what form to transmit personal information, you should note that information sent by e-mail through the internet may be intercepted.

Appendix 2

Disclosure of information about patients to the Driver and Vehicle Licensing Agency (DVLA)

1. 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.

2. Therefore, 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.

3. 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.

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

5. 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.

6. 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.

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