Executive summary
Between November 2015 and February 2016 we carried out a consultation on the revised Confidentiality guidance and seven associated explanatory statements. We received 193 written responses across four questionnaires, and engaged directly with over 1,000 individual doctors and members of the public.

The overall reception of the draft guidance was strongly positive and respondents generally considered the guidance to be clear, helpful, and to strike the right balance between providing advice and setting expectations of the standards expected of doctors. Comments therefore tended to focus on points of technical, legal and practical detail, although we have made some changes to the structure of the guidance, and we intend to withdraw two explanatory statements that we think are no longer needed.

It is intended that the revised guidance will be published in January 2017 and will come into effect three months later.

Recommendations
The Strategy and Policy Board is asked to:

- a Note the summary of consultation activities at Annex C and the summary of consultation outcomes at Annex D.
- b Approve the text of the guidance Confidentiality, at Annex A, and the five explanatory statements, at Annex B.
- c Agree that the guidance should be brought to Council consider the guidance at its closed session on 9 November and to approve publication at its meeting on 14 December 2016.
Background

1 In late 2014 we began work to revise our 2009 Confidentiality guidance and the associated explanatory guidance and materials, to ensure that they remain compatible with the law and relevant to medical practice. Between November 2015 and February 2016 we carried out a consultation on the revised Confidentiality guidance, the development of which was overseen by an expert task and finish group, with clinical, legal and lay representation. A list of members is at Annex E.

2 The consultation responses were analysed in March 2016 and proposals for redrafting the guidance were considered by the task and finish group at meetings in April and May, and by email circulation in June 2016. The guidance then was reviewed by legal counsel in July and was edited for tone of voice in August 2016.

3 It is intended that the revised guidance, at Annexes A and B, will be published in January 2017 and will come into effect three months later.

Consultation activities

4 The consultation was promoted with key interests through a number of different channels which included targeted stakeholder e-mailing activity including patient groups, monthly e-bulletin, medical trade press, national media and social media.

5 We employed three methods to gather views on the draft and the issues raised in the guidance: targeted consultation questionnaires; direct engagement with doctors, patients, carers and key policy stakeholders; and research commissioned from Ipsos MORI exploring patient and public attitudes towards particular issues in the draft guidance.

6 In total we received 193 written responses across four questionnaires. 49 responses came from organisations and the rest were from individuals (including 65 doctors, 30 members of the public, and 15 respondents who identified themselves as ‘other healthcare professionals’). This level of response is comparable with the response to the last GMC consultation on confidentiality (and is higher than the response levels to other recent consultations on information governance matters run by government departments), and the quality of engagement was very high, but there does seem to be an ongoing challenge in terms of encouraging written responses, especially from individual doctors and members of the public.

7 In anticipation of this, we ran an extensive programme of face to face engagement during the consultation, reaching just over 1,000 individuals through the combined efforts of the Regional Liaison Service (RLS), Devolved Offices, and policy team. We also commissioned Ipsos MORI to undertake research with groups of patients and members of the public that we had identified as potentially having particular concerns around confidentiality but who might be less likely to take part in a formal written consultation, and who we would find it difficult to identify or recruit to our
own engagement events. Participants included older people resident in care homes, members of the gypsy and traveller community, people who have experienced domestic violence and asylum seekers and refugees. A detailed summary of consultation activity is at Annex C.

Consultation outcomes

8 The overall reception of the draft guidance was strongly positive and respondents generally considered the guidance to be clear, helpful, and to strike the right balance between providing advice and setting expectations of the standards expected of doctors. In particular, there was strong support of our decision to structure the guidance according to the purpose of a disclosure (direct care, other purposes), rather than according to the legal basis for a disclosure, as in the current guidance. The purpose of this change was to make the guidance easier to navigate and apply in practice and, with some caveats, respondents liked the new approach.

9 Comments therefore tended to focus on points of technical, legal and practical detail. A summary of the main themes arising in consultation responses and how we have responded to them is at Annex D, but the headline issues were these.

- **Structure.** Respondents welcomed the re-structure of the guidance but said that the distinction we drew between non-care and indirect care purposes was artificial, created unnecessary repetition, and likely to be confusing. We have therefore collapsed this distinction in the revised guidance.

- **The public interest justification for disclosing identifiable information for purposes such as research.** We received significant challenge on this section of the draft guidance from the BMA and other expert respondents, on the grounds that they thought it might encourage doctors to act unlawfully and unethically. We are confident that our analysis of the law is correct (having confirmed it with leading counsel) but we have made changes to the expression of the professional duties which the BMA is content with.

- **Disclosure of information about adults with capacity, without consent, for their own protection.** This is an uncertain area of ethics and law, and neither the responses to the written consultation, nor a subsequent roundtable discussion with a range of experts, gave us a clear answer to the question of whether and, if so, when such disclosures could be justified. Following advice from leading counsel we have arrived at a policy position which aligns with advice provided by the BMA and is probably as far as we can go to be helpful in this very complex area.

- **Legal annex.** The legal annex was warmly welcomed by many respondents who found it a very helpful reference in a highly complex area, although there were calls to make clearer the territorial extent of legislation listed. We are however
considering whether it should remain part of the guidance, or whether it should be published as a separate document, as it will need to be updated regularly.

10 Responses to the explanatory statements were similarly positive, although we have subsequently decided to withdraw the explanatory statement on disclosures for financial and administrative purposes as we think it is redundant as a result of the way we have restructured the core guidance. We are also proposing to withdraw the explanatory statement on reporting gunshot and knife wounds as the need for it appears to have waned, although we are checking this view with key stakeholders.

Internal review, legal review and independent audit

11 The guidance has had input from colleagues in fitness to practise and the legal team, and they are content that the standards in the draft can be effectively applied within the context of Fitness to Practise decision making. The guidance has also been edited for tone of voice by the publications team.

12 The draft guidance has also been reviewed by legal counsel in the four countries, all of whom have confirmed that that the draft guidance is consistent with the legal frameworks in their jurisdictions. We are seeking clarification from Counsel for England and Wales on two points, but we do not expect any further significant changes to the guidance.

13 An independent audit of the consultation analysis found some minor inconsistencies in the ways statistics were reported in the analysis papers, and an oversight in one piece of analysis due to a mislabelling of a spreadsheet, but the overall conclusion of the audit was that ‘the analysis of the consultation is an accurate reflection of respondents’ views’.

Launch and implementation plans

14 It is anticipated that the guidance will be launched in January 2017, and will come into effect three months later. The guidance will be designed to be accessed in interactive digital, as well as paper, formats in line with the principles of our 'digital first' strategy.

15 The priority for launch will be to raise awareness of the new guidance with doctors, as well as the wide range of organisations that are likely to quote from our current guidance. Over the autumn we will work up detailed launch and communications plans, and design materials (for example based on the flow chart in the guidance, or the key principles set out at the front of the guidance) that help users to navigate the guidance.

16 The existing guidance and associated materials will be in use until the new guidance comes into effect so, to reduce the likelihood of confusion, we will not update references in current guidance or case studies, or launch new case studies, when the
guidance is first published. Instead, we will launch a suite of supporting materials when the new guidance comes into effect, which is expected to be in April 2017.

Equality and diversity

17 We have taken steps to comply with the public sector equality duty, both through our own engagement and through the Ipsos Mori work, and by actively considering equality issues as we drafted the guidance. We will also raise doctors’ awareness of the issues faced by groups from the protected characteristics through case studies or hot topics.

Next steps

18 Subject to the Board’s agreement, we will ask Council to consider the guidance at its closed session on 9 November 2016 and to approve the final guidance at its meeting on 14 December 2016 with a view to launching the guidance in January 2017.
6 - Confidentiality guidance

Confidentiality:
good practice in handling patient information
Post consultation draft 1.5.5
Confidentiality:

*good practice in handling patient information*

Post consultation draft 1.5.5
[Duties of a doctor to be included on inside cover]
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About this guidance

1 Our core guidance for doctors, *Good medical practice*, makes clear that patients have a right to expect that their personal information will be held in confidence by their doctors. This guidance sets out the principles of confidentiality and respect for patients’ privacy that you are expected to understand and follow.

2 This guidance outlines the framework for considering when to disclose patients’ personal information and then applies that framework to:
   - disclosures to support the direct care of an individual patient
   - disclosures for the protection of patients and others
   - disclosures for all other purposes.

   This guidance also sets out the responsibilities of all doctors for managing and protecting patient information.

3 In this guidance, we use the terms ‘you must’ and ‘you should’ in the following ways.
   - ‘You must’ is used for an overriding duty or principle.
   - ‘You should’ is used when we are providing an explanation of how you will meet the overriding duty.
   - ‘You should’ is also used where the duty or principle will not apply in all situations or circumstances, or where there are factors outside your control that affect whether or how you can follow the guidance.

4 You must use your judgement to apply the principles in this guidance to the situations you face as a doctor, whether or not you hold a licence to practise and whether or not you routinely see patients. If in doubt, you should seek the advice of an experienced colleague, a Caldicott or data guardian\(^1\) or equivalent, your defence body or professional association, or seek independent legal advice.

5 You must be prepared to explain and justify your decisions and actions. Serious or persistent failure to follow this guidance will put your registration at risk.
Other materials available

6 Further explanatory guidance is available on our website explaining how these principles apply in situations doctors often encounter or find hard to deal with. At the time of publishing this core guidance, we are also publishing explanatory guidance on:

- patients’ fitness to drive and reporting concerns to the DVLA or DVA
- disclosing information about serious communicable diseases
- disclosing information for employment, insurance and similar purposes
- disclosing information for education and training
- responding to criticism in the media.
Ethical and legal duties of confidentiality

7 Trust is an essential part of the doctor-patient relationship and confidentiality is central to this. Patients may avoid seeking medical help, or may under-report symptoms, if they think their personal information will be disclosed\(^2\) by doctors without consent, or without the chance to have some control over the timing or amount of information shared.

8 Doctors are therefore under both ethical and legal duties to protect patients’ personal information from improper disclosure. But appropriate information sharing is an essential part of the provision of safe and effective care. Patients may be put at risk if those who are providing their care do not have access to relevant, accurate and up-to-date information about them.

9 There are also important uses of patient information for purposes other than direct care. Some of these are indirectly related to patient care, in that they enable health services to function efficiently and safely. For example, large volumes of patient information are used for purposes such as medical research, service planning and financial audit. Other uses are not directly related to the provision of healthcare but serve wider public interests, such as disclosures for public protection reasons.

10 Doctors’ roles are continuing to evolve and change. It is likely to be more challenging to make sure there is a legal and ethical basis for using patient information in a complex health and social care environment than in the context of a single doctor-patient relationship. In this guidance, we aim to support individual doctors to meet their professional responsibilities while working within these complex systems.
The main principles of this guidance

The advice in this guidance is underpinned by the following eight principles.3

- **Use the minimum necessary personal information.** Use anonymised information if it is practicable to do so and if it will serve the purpose.

- **Manage and protect information.** Make sure any personal information you hold or control is effectively protected at all times against improper access, disclosure or loss.

- **Be aware of your responsibilities.** Develop and maintain an understanding of information governance that is appropriate to your role.

- **Comply with the law.** Be satisfied that you are handling personal information lawfully.

- **Share relevant information for direct care** as long as you are satisfied the patient can easily access information that explains how their information will be used and that they have the right to object, and you have no reason to believe the patient has objected.

- **Ask for explicit consent** to disclose identifiable information about patients for purposes other than their care or local clinical audit, unless the disclosure is required by law or can be justified in the public interest.

- **Tell patients** about disclosures of personal information you make that they would not reasonably expect, or check they have received information about such disclosures, unless that is not practicable or would undermine the purpose of the disclosure.

- **Support patients to access their information.** Respect, and help patients exercise, their legal rights to be informed about how their information will be used and to have access to, or copies of, their health records.
A framework for considering whether to disclose a patients’ personal information

Acting within the law

12 Doctors, like everyone else, must comply with the law when using, accessing or disclosing personal information. The law governing the use and disclosure of personal information is complex and varies across the four countries of the UK.

13 In the legal annex, we summarise some key elements of the relevant law, including the requirements of the common law, the Data Protection Act 1998 and the Human Rights Act 1998, and other laws that require or permit the disclosure of patient information. In the main body of the guidance, we give advice on how to apply ethical and legal principles in practice, but we do not refer to specific pieces of law unless it is necessary to do so. If you are not sure how the law applies in a particular situation, you should consult a Caldicott or data guardian, your defence body or professional association, or seek independent legal advice.

When you can disclose personal information

14 Confidentiality is an important ethical and legal duty but it is not absolute. You may disclose personal information without breaching duties of confidentiality when any of the following circumstances apply.

a The patient consents, whether implicitly for the sake of their own care or for local clinical audit, or explicitly for other purposes (see paragraphs 18–20).

b The disclosure is of overall benefit to a patient who lacks the capacity to consent (see paragraphs 46–54).

c The disclosure is required by law (see paragraphs 22–24), or the disclosure is permitted or has been approved under a statutory process which sets aside the common law duty of confidentiality (see paragraphs 25–26).

d The disclosure can be justified in the public interest (see paragraphs 27–28).

15 When disclosing information about a patient you must:
a use anonymised information if it is practicable to do so and if it will serve the purpose
b be satisfied the patient:
   i has ready access to information explaining how their information will be used for their direct care or local clinical audit, and that they have the right to object
   ii has not objected.
c get the patient’s explicit consent if identifiable information is to be disclosed for purposes other than their direct care or local clinical audit, unless the disclosure is required by law or can be justified in the public interest
d keep disclosures to the minimum necessary for the purpose
e follow all relevant legal requirements, including the common law and data protection law.5

16 When you are satisfied that information should be disclosed, you should act promptly to disclose all relevant information.

17 You must tell patients about disclosures you make that they would not reasonably expect, or check they have received information about such disclosures, unless that is not practicable or would undermine the purpose of the disclosure – for example, by prejudicing the prevention or detection of serious crime.

**Disclosing information with a patient's consent**

18 Asking for a patient’s consent to disclose information shows respect, and is part of good communication between doctors and patients.6 Consent may be explicit or implied.

- Explicit (also known as express) consent is given when a patient actively agrees, either orally or in writing, to the use or disclosure of information.

- Implied consent refers to circumstances in which it would be reasonable to infer that the patient agrees to the use of the information, even though this has not been directly expressed.
19 You may disclose information on the basis of implied consent for direct care when the conditions in paragraphs 33 and 34 are met, and for local clinical audit when the conditions in paragraph 101 are met. In other cases, you should ask for explicit consent to disclose personal information unless it is not appropriate or practicable to do so. For example, this might be because:

- the disclosure is required by law (see paragraphs 22–24)
- you are satisfied that informed consent has already been obtained by a suitable person
- the patient does not have capacity to make the decision. In such a case, you should follow the guidance on disclosures about patients who lack capacity to consent (see paragraphs 46–54)
- you have reason to believe that seeking consent would put you or others at risk of serious harm
- seeking consent would be likely to undermine the purpose of the disclosure, for example by prejudicing the prevention or detection of serious crime
- action must be taken quickly, for example in the detection or control of outbreaks of some communicable diseases where there is insufficient time to contact the patient
- seeking consent is not feasible given the number or age of records, or the likely traceability of patients.

20 If you disclose personal information without consent, you must be satisfied that there is a legal basis for breaching confidentiality (see paragraph 14). You must also be satisfied that the other relevant requirements for disclosing information are met (see paragraph 15).

**Disclosing information about a patient who lacks the capacity to consent**

21 You may disclose relevant personal information about a patient who lacks the capacity to consent if it is of overall benefit to the patient. You can find more guidance on this in paragraphs 46–54.
Disclosures required by law

22 You must disclose information if it is required by statute, or if you are ordered to do so by a judge or presiding officer of a court (see paragraphs 92–99). Examples of legal requirements to disclose information about patients are given in the legal annex.

23 You should satisfy yourself that the disclosure is required by law and you should only disclose information that is relevant to the request. Wherever practicable, you should tell patients about such disclosures, unless that would undermine the purpose, for example by prejudicing the prevention or detection of serious crime.

24 Laws and regulations sometimes permit, but do not require, the disclosure of personal information. If a disclosure is permitted but not required by law, you must be satisfied that there is a legal basis for breaching confidentiality (see paragraph 14). You must also be satisfied that the other relevant requirements for disclosing information are met (see paragraph 15).

Disclosures with specific statutory support

25 You may disclose personal information without consent if the disclosure is permitted or has been approved under section 251 of the National Health Service Act 2006 (which applies in England and Wales) or the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016. These pieces of law allow the common law duty of confidentiality to be set aside for defined purposes where it is not possible to use anonymised information and where seeking consent is not practicable. There is no comparable legal framework in Scotland.

26 If you know that a patient has objected to information being disclosed for purposes other than their direct care, you should not usually disclose the information unless it is required under the regulations. You can find more guidance on disclosures with specific statutory support in paragraphs 108–110.

Disclosures in the public interest

27 Confidential medical care is recognised in law as being in the public interest. The fact that people are encouraged to seek advice and treatment benefits society as a whole as well as the
individual. But there can be a public interest in disclosing information to protect individuals or society from risks of serious harm, such as from serious communicable diseases or serious crime. You can find guidance on disclosing information in the public interest to prevent death or serious harm in paragraphs 68–75.

28 There may also be circumstances in which disclosing personal information without consent is justified in the public interest for important public benefits, other than to prevent death or serious harm, if there is no reasonably practicable alternative to using personal information. The circumstances in which the public interest would justify such disclosures are uncertain, however, so you should seek the advice of a Caldicott or data guardian or a legal adviser who is not directly connected with the use for which the disclosure is being considered before making the disclosure. You can find further guidance in paragraphs 111–117.

Disclosures prohibited by law

29 Health professionals are required by certain laws to restrict the disclosure of some types of information. You can find examples of disclosures prohibited by law in the legal annex.
Making the decision about whether to disclose patients’ personal information

Flowchart

As a rule, personal information about patients should not be disclosed unless it is necessary. The following flowchart can help you decide whether personal information needs to be disclosed and, if so, what the justification is for doing so.

1. Would anonymised information be sufficient for the purpose?  → Yes
   No
   2. Is it appropriate or practicable to seek explicit consent? **See paragraph 19.**  → Yes
      No
      3. Is it reasonable to rely on implied consent? **See paragraphs 33–34 and 101.**  → Yes
         No
         4. Is the disclosure about a patient who does not have capacity to make the decision and of overall benefit to that patient? **See paragraphs 46–54.**  → No
            Yes
            5. Is the disclosure of identifiable information required by law?  → Yes
               No
               6. Is the disclosure of identifiable information approved through a statutory process?  → Yes
                  No
                  7. Is disclosure justified in the public interest? **See paragraphs 68–75 and 111–117**  → Yes
                     No
                     8. No obvious legal basis for disclosure. Ask person or body requesting information to identify the legal basis.

Ensure that appropriate controls are in place to minimise the risks of individual patients being re-identified. The controls that are required will depend on the risk of re-identification. **See paragraphs 85–81.**

Has the patient given consent?  → No
   Yes
   9. Disclose or provide access to relevant information. Tell patients about disclosures if practicable. **See paragraphs 15–17.**

Only disclose or provide access to information that is relevant, and only in the way required by law. Tell patients about disclosures if practicable. **See paragraphs 52–59.**

You may disclose or provide access to relevant information. If you are aware that a patient has objected to information being disclosed for such purposes you should not usually disclose information unless it is required under the regulations. **See paragraphs 108–110.**
Using and disclosing patient information for direct care purposes

Sharing information for direct care

31 Appropriate information sharing is an essential part of the provision of safe and effective care. Patients may be put at risk if those who provide their care do not have access to relevant, accurate and up-to-date information about them. Multidisciplinary and multi-agency teamwork is also placing increasing emphasis on integrated care and partnership working, and information sharing is central to this, but information must be shared within the framework provided by law and ethics.

Sharing information within the direct care team on the basis of implied consent

32 Most patients understand and expect that relevant information must be shared within the direct care team to provide their care. You should share relevant information with those who provide or support direct care to a patient, unless the patient has objected (see paragraphs 35 and 36).

33 The usual basis for sharing information for direct care is the patient’s consent, whether that is explicit or implied (see paragraph 18 for definitions). You may rely on implied consent to access relevant information about the patient or to share it with those who provide (or support the provision of) direct care to the patient if all of the following are met.

a You are accessing the information to provide or support the individual patient’s direct care, or are satisfied that the person you are sharing the information with is accessing or receiving it for this purpose.

b Information is readily available to patients, explaining how their information will be used and that they have the right to object. This can be provided in leaflets and posters, on websites, and face to face. It should be tailored to patients’ identified communication requirements as far as practicable.

c You have no reason to believe the patient has objected.
You are satisfied that anyone you disclose personal information to understands that you are giving it to them in confidence, which they must respect.

34 If you suspect a patient would be surprised to learn about how you are accessing or disclosing their personal information, you should ask for explicit consent unless it is not practicable to do so (see paragraph 19). For example, a patient may not expect you to have access to information from another healthcare provider or agency on a shared record.

Patient objections to sharing information for direct care

35 If a patient objects to particular personal information being shared for their direct care, you should not disclose the information unless it would be justified in the public interest, or is of overall benefit to a patient who lacks the capacity to make the decision. You can find further guidance on disclosures of information about adults who lack capacity to consent in paragraphs 46–54.

36 You should explain to the patient the potential consequences of a decision not to allow personal information to be shared with others who are providing their care. You should also consider with the patient whether any compromise can be reached. If, after discussion, a patient who has capacity to make the decision still objects to the disclosure of personal information that you are convinced is essential to provide safe care, you should explain that you cannot refer them or otherwise arrange for their treatment without also disclosing that information.

If a patient cannot be informed

37 Circumstances may arise in which a patient cannot be informed about the disclosure of personal information, for example in a medical emergency. In such cases, you should pass relevant information promptly to those providing the patient’s care.
If the patient regains the capacity to understand, you should inform them how their personal information was disclosed if it was in a way they would not reasonably expect.

Sharing information with those close to the patient

You must be considerate to those close to the patient and be sensitive and responsive in giving them information and support, while respecting the patient’s right to confidentiality.

Establishing what the patient wants

The people close to a patient can play a significant role in supporting, or caring for, the patient and they may want or need information about the patient’s diagnosis, treatment or care. Early discussions about the patient’s wishes can help to avoid disclosures they might object to. Such discussions can also help avoid misunderstandings with, or causing offence or distress to, anyone the patient would want information to be shared with.

You should establish with the patient what information they want you to share, with whom, and in what circumstances. This will be particularly important if the patient has fluctuating or diminished capacity or is likely to lose capacity, even temporarily. You should document the patient’s wishes in their records.

Abiding by the patient’s wishes

If a patient who has capacity to make the decision refuses permission for information to be shared with a particular person or group of people, it may be appropriate to encourage the patient to reconsider that decision if sharing the information may be beneficial to the patient’s care and support. You must, however, abide by the patient’s wishes, unless disclosure would be justified in the public interest (see paragraphs 68–75).
43 If a patient lacks capacity to make the decision, it is reasonable to assume the patient would want those closest to them to be kept informed of their general condition and prognosis, unless they indicate (or have previously indicated) otherwise. You can find detailed advice on considering disclosures about patients who lack capacity to consent in paragraphs 46–54.

Listening to those close to the patient

44 In most cases, discussions with those close to the patient will take place with the patient’s knowledge and consent. But if someone close to the patient wants to discuss their concerns about the patient’s health without involving the patient, you should not refuse to listen to their views or concerns on the grounds of confidentiality. The information they give you might be helpful in your care of the patient.

45 You should, however, consider whether your patient would consider you listening to the views or concerns of others to be a breach of trust, particularly if they have asked you not to listen to specific people. You should also make clear that, while it is not a breach of confidentiality to listen to their concerns, you might need to tell the patient about information you have received from others – for example, if it has influenced your assessment and treatment of the patient. You should also take care not to disclose confidential information unintentionally – for example, by confirming or denying the person’s perceptions about the patient’s health.

Disclosing information about a patient who lacks capacity to consent

46 You must work on the presumption that every adult patient has the capacity to make decisions about the disclosure of their personal information. You must not assume a patient lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including mental illness), beliefs, apparent inability to communicate, or because they make a decision you disagree with.
47 You must assess a patient’s capacity to make a particular decision at the time it needs to be made, recognising that fluctuations in a patient’s condition may affect their ability to understand, retain or weigh up information, or communicate their wishes.

48 We give detailed advice on assessing a patient’s mental capacity in our guidance *Consent: patients and doctors making decisions together*. Practical guidance is also given in the *Adults with Incapacity (Scotland) Act 2000* and *Mental Capacity Act 2005* codes of practice.\(^\text{13}\)

**Considering the disclosure**

49 You may disclose personal information if it is of overall benefit to a patient who lacks the capacity to consent. When making the decision about whether to disclose information about a patient who lacks capacity to consent, you must:

a. make the care of the patient your first concern
b. respect the patient’s dignity and privacy
c. support and encourage the patient to be involved, as far as they want and are able, in decisions about disclosure of their personal information.

50 You must also consider:

a. whether the patient’s lack of capacity is permanent or temporary and, if temporary, whether the decision to disclose could reasonably wait until they regain capacity
b. any evidence of the patient’s previously expressed preferences
c. the views of anyone the patient asks you to consult, or who has legal authority to make a decision on their behalf, or has been appointed to represent them
d. the views of people close to the patient on the patient’s preferences, feelings, beliefs and values, and whether they consider the proposed disclosure to be of overall benefit to the patient
e. what you and the rest of the healthcare team know about the patient’s wishes, feelings, beliefs and values.
51 You might need to share personal information with a patient’s relatives, friends or carers to enable you to assess the overall benefit to the patient. But that does not mean they have a general right of access to the patient’s records or to be given irrelevant information about, for example, the patient’s past healthcare.

52 You should share relevant information with anyone who is authorised to make health and welfare decisions on behalf of, or who is appointed to support and represent, a patient who lacks capacity to give consent. This might be a welfare attorney, a court-appointed deputy or guardian, or an independent mental capacity advocate. You should also share information with independent mental health advocates in some circumstances.¹⁴

If a patient who lacks capacity to make the decision asks you not to disclose information

53 If a patient asks you not to disclose personal information about their condition or treatment, and you believe they lack capacity to make that decision, you should try to persuade them to allow an appropriate person to be given relevant information about their care. In some cases, disclosing information will be required or necessary, for example under the provisions of mental health and mental capacity laws (see paragraph 52 and the legal annex).

54 If the patient still does not want you to disclose information, but you consider that it would be of overall benefit to the patient and you believe they lack capacity to make that decision, you may disclose relevant information to an appropriate person or authority. In such cases, you should tell the patient before disclosing the information and, if appropriate, seek and carefully consider the views of an advocate or carer. You must document in the patient’s records your discussions and the reasons for deciding to disclose the information.
Using and disclosing patient information for the protection of patients and others

**Patients who may be at risk of harm**

55 All patients have the right to a confidential medical service. Challenging situations can however arise when confidentiality rights must be balanced against duties to protect and promote the health and welfare of patients who may be unable to protect themselves.

**Disclosing information about children who may be at risk of harm**

56 For general advice on confidentiality when using, accessing or disclosing information about children and young people, see our guidance 0–18 years: guidance for all doctors.\(^{15}\) For specific guidance on confidentiality in the context of child protection, see our guidance Protecting children and young people: the responsibilities of all doctors.\(^{16}\)

**Disclosing information about adults who may be at risk of harm**

57 As a rule, you should make decisions about how best to support and protect adult patients in partnership with them, and should focus on empowering patients to make decisions in their own interests. You must support and encourage patients to be involved, as far as they want and are able, in decisions about disclosing their personal information.

**Legal requirements to disclose information about adults at risk**

58 There are various legal requirements to disclose information about adults who are known or considered to be at risk of, or to have suffered, abuse or neglect.\(^{17}\) You must disclose information if it is required by law. You should:

- a satisfy yourself that the disclosure is required by law
- b only disclose information that is relevant to the request, and only in the way required by the law
- c tell patients about such disclosures whenever practicable, unless it would undermine the purpose of the disclosure to do so.
You can find general advice about disclosures required or permitted by law in paragraphs 22–24.

**Disclosing information when a patient who lacks capacity to consent may be at risk of serious harm**

You must disclose personal information about an adult who may be at risk of serious harm if it is required by law (see paragraphs 58 and 59). Even if there is no legal requirement to do so, you must give information promptly to an appropriate responsible person or authority if you believe a patient who lacks capacity to consent is experiencing, or at risk of, neglect or physical, sexual or emotional abuse, or any other kind of serious harm, unless it is not of overall benefit to the patient to do so.

If you believe it is not of overall benefit to the patient to disclose their personal information (and it is not required by law), you should discuss the issues with an experienced colleague. If you decide not to disclose information, you must document in the patient’s records your discussions and the reasons for deciding not to disclose. You must be able to justify your decision.

**Disclosing information to protect adults who have capacity**

**The rights of adults who have capacity to make their own decisions**

As a principle, adults who have capacity are entitled to make their own decisions, even if others consider those decisions to be irrational or unwise. You should usually ask for consent before disclosing personal information about a patient if disclosure is not required by law, and it is practicable to do so. You can find examples of when it might not be practicable to ask for consent in paragraph 19.

If an adult patient who has capacity to make the decision refuses to consent to information being disclosed that you consider necessary for their protection, you
should explore their reasons for this. It may be appropriate to encourage the patient to consent to the disclosure and to warn them of the risks of refusing to consent.

**64** You should, however, usually abide by the patient’s refusal to consent to disclosure, even if their decision leaves them (but no one else) at risk of death or serious harm.\(^{18,19}\) You should do your best to give the patient the information and support they need to make decisions in their own interests – for example, by arranging contact with agencies to support people who experience domestic violence.\(^{20}\) Adults who initially refuse offers of assistance may change their decision over time.

**Disclosing information to protect others**

**65** Doctors owe a duty of confidentiality to their patients, but they also have a wider duty to protect and promote the health of patients and the public.\(^{21}\)

**Legal requirements to disclose information for public protection purposes**

**66** Some laws require disclosure of patient information for purposes such as the notification of infectious diseases and the prevention of terrorism. You must disclose information if it is required by law (see paragraphs 92–99).

**Disclosing information with consent**

**67** You should ask for a patient’s consent to disclose information for the protection of others unless it is not safe or practicable to do so (see paragraph 19), or the information is required by law. You should consider any reasons given for refusal.

**Disclosing information in the public interest**

**68** Confidential medical care is recognised in law as being in the public interest. The fact that people are encouraged to seek advice and treatment benefits society as a whole as well as the individual. But there can be a public interest in disclosing information to protect individuals or society from risks of serious harm, such as from serious communicable diseases or serious crime.\(^{22}\)
69 If it is not practicable to seek consent, and in exceptional cases where a patient has refused consent, disclosing personal information may be justified in the public interest if failure to do so may expose others to a risk of death or serious harm. The benefits to an individual or to society of the disclosure must outweigh both the public and the patient’s interest in keeping the information confidential.

70 Such a situation might arise, for example, if a disclosure would be likely to be necessary for the prevention, detection or prosecution of serious crime, especially crimes against the person. When victims of violence refuse police assistance, disclosure may still be justified if others remain at risk, for example from someone who is prepared to use weapons, or from domestic violence when children or others may be at risk.

71 Other examples of situations in which failure to disclose information may expose others to a risk of death or serious harm include when a patient is not fit to drive\(^2\), or has been diagnosed with a serious communicable disease,\(^3\) or poses a serious risk to others through being unfit for work.\(^4\)

72 When deciding whether the public interest in disclosing information outweighs patients’ and the public interest in keeping the information confidential, you must consider:

   a  the potential harm or distress to the patient arising from the disclosure – for example, in terms of their future engagement with treatment and their overall health

   b  the potential harm to trust in doctors generally – for example, if it is widely perceived that doctors will readily disclose information about patients without consent

   c  the potential harm to others (whether to a specific person or people, or to the public more broadly) if the information is not disclosed

   d  the potential benefits to an individual or to society arising from the release of the information
e the nature of the information to be disclosed, and any views expressed by the patient
f whether the harms can be avoided or benefits gained without breaching the patient’s privacy or, if not, what is the minimum intrusion.

73 If you consider that failure to disclose the information would leave individuals or society exposed to a risk so serious that it outweighs the patient’s and the public interest in maintaining confidentiality, you should disclose relevant information promptly to an appropriate person or authority. You should inform the patient before disclosing the information, if it is practicable and safe to do so, even if you intend to disclose without their consent.

74 Decisions about whether or not disclosure without consent can be justified in the public interest can be complex. Where practicable, you should seek advice from a Caldicott or data guardian or similar expert adviser who is not directly connected with the use for which disclosure is being considered. If possible, you should do this without revealing the identity of the patient.

75 You must document in the patient’s record your reasons for disclosing information without consent and any steps you have taken to seek the patient’s consent, to inform them about the disclosure, or your reasons for not doing so.

Responding to requests for information

76 You must consider seriously all requests for relevant information about patients who may pose a risk of serious harm to others. For example, you must participate in procedures set up to protect the public from violent and sex offenders, such as multi-agency public protection arrangements (MAPPA) in England, Wales and Scotland and public protection arrangements in Northern Ireland (PPANI). You must also consider seriously all requests for information needed for formal reviews (such as inquests and inquiries, serious or significant case reviews, case management reviews, and domestic homicide reviews) that are established to learn lessons and to improve systems and services.
If you disclose personal information without consent, you must be satisfied that there is a legal basis for breaching confidentiality (see paragraph 14). You must also be satisfied that the other relevant requirements for disclosing information are met (see paragraph 15).

**Disclosing genetic and other shared information**

Genetic and some other information about your patient might also be information about others with whom the patient shares genetic or other links. The diagnosis of a patient’s illness might, for example, point to the certainty or likelihood of the same illness in a blood relative.

Most patients will readily share information about their own health with their children and other relatives, particularly if they are told it might help those relatives to:
- get prophylaxis or other preventative treatments or interventions
- make use of increased surveillance or other investigations
- prepare for potential health problems.

A patient may also have agreed to sharing information as part of the standard consent processes when they accessed clinical genetics services.

If a patient refuses to consent to information being disclosed that would benefit others, disclosure might still be justified in the public interest if failure to disclose the information leaves others at risk of death or serious harm (see paragraphs 68–75). If a patient refuses consent to disclosure, you will need to balance your duty to make the care of your patient your first concern against your duty to help protect the other person from serious harm.

If practicable, you should not disclose the patient’s identity in contacting and advising others about the risks they face.
Using and disclosing patient information for the delivery of health and social care, research and other purposes

82 Many important uses of patient information contribute to the overall delivery of health and social care. Examples include health services management, research, epidemiology, public health surveillance, and education and training. Without information about patients the health and social care system would be unable to plan, develop, innovate, conduct research or be publicly accountable for the services it provides.

83 There are also important uses of patient information that are not connected to the delivery of health or social care, but which serve wider purposes. These include disclosures for the administration of justice, and for purposes such as financial audit and insurance or benefits claims.

84 Anonymised information will usually be sufficient for purposes other than the direct care of the patient and you must use it in preference to personal information where possible. If you disclose identifiable information for purposes other than a patient’s direct care or local clinical audit you must be satisfied that there is a legal basis for breaching confidentiality.

85 You may disclose personal information without breaching duties of confidentiality when any of the following circumstances apply.

a The disclosure is required by law (see paragraphs 92–99).

b The patient has given explicit consent (see paragraph 100).

c The disclosure is approved through a statutory process which sets aside the common law duty of confidentiality (see paragraphs 108–110).

d The disclosure can, exceptionally, be justified in the public interest (see paragraphs 111–117).
You must also be satisfied that the other relevant requirements for disclosing information are met (see paragraph 15).

**Anonymised information**

86 The Information Commissioner’s Office (ICO) anonymisation code of practice considers data to be anonymised if it does not itself identify any individual, and if it is unlikely to allow any individual to be identified through its combination with other data.\(^2^9\) Simply removing the patient’s name, age, address or other personal identifiers is unlikely to be enough to anonymise information to this standard.\(^3^0\)

87 The code also makes clear that different types of anonymised data pose different levels of re-identification risk. For example, data sets with small numbers may present a higher risk of re-identification than large data sets. The risk of re-identification will also vary according to the environment in which the information is held. For example, an anonymised dataset disclosed into a secure and controlled environment could remain anonymous even though the same dataset could not be made publically available because of the likelihood of individuals being identified.

88 You should follow the ICO anonymisation code of practice, or guidance that is consistent with the ICO code, or seek expert advice if you have a role in anonymising information or disclosing anonymised information.

**The process of anonymising information**

89 Information may be anonymised by a member of the direct care team who has the knowledge, skills and experience to carry out the anonymisation competently, or will be adequately supervised.

90 If it is not practicable for the information to be anonymised within the direct care team it may be anonymised by a data processor under contract, as long as there is a legal basis for any breach of confidentiality (see paragraph 85), the requirements of data protection law are met (see the legal annex) and appropriate controls are in place to protect the information (see paragraph 91).
Disclosing anonymised information

91 If you decide to disclose anonymised information, you must be satisfied that appropriate controls are in place to minimise the risk of individual patients being identified. The controls that are needed will depend on the risk of re-identification, and might include signed contracts or agreements that contain controls on how the information will be used, kept and destroyed, as well as restrictions to prevent individuals being identified. You should refer to specialist advice or guidance when assessing risk, or considering what level of control is appropriate.31

Disclosures required by statutes or the courts

Disclosure required by statute

92 There are a large number of laws that require disclosure of patient information – for purposes as diverse as the notification of infectious diseases, the provision of health and social care services, the prevention of terrorism and the investigation of road accidents. You can find examples in the legal annex.

93 You must disclose information if it is required by law. You should:

   a  satisfy yourself that personal information is needed, and the disclosure is required by law
   b  only disclose information relevant to the request, and only in the way required by the law
   c  tell patients about such disclosures whenever practicable, unless it would undermine the purpose of the disclosure to do so
   d  abide by patient objections where there is provision to do so.32

94 You can find general advice about disclosures that are required or permitted by law in paragraphs 22–24.
Disclosing information to courts or in connection with litigation

95 The courts, both civil and criminal, have powers to order disclosure of information in various circumstances. You must disclose information if ordered to do so by a judge or presiding officer of a court.

96 You should only disclose information that is required by the court. You should object to the judge or the presiding officer if attempts are made to compel you to disclose what appears to you to be irrelevant information, such as information about a patient’s relative who is not involved in the proceedings. You should also tell the judge or the presiding officer if you think disclosing the information might put someone at risk of harm.

97 If disclosure is ordered, and you do not understand the basis for this, you should ask the court or a legal adviser to explain it to you. You should also tell the patient whose information the court has asked for what information you will disclose in response to the order, unless that is not practicable or would undermine the purpose for which disclosure is sought.

98 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 explicit consent, unless it is required by law, or ordered by a court, or can be justified in the public interest. You may disclose information without consent to your own legal adviser to get their advice.

99 In Scotland, the system of precognition means there can be limited disclosure of information in advance of a criminal trial, to both the Crown and defence, without the patient’s explicit consent. You should cooperate with precognition, but the disclosure must be confined solely to the nature of injuries, the patient’s mental state, or pre-existing conditions or health, documented by the examining doctor, and their likely causes. If they want further information, either side may apply to the court to take a precognition on oath. If that happens, you will be given advance warning and you should seek legal advice about what you may disclose.33

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www.gmc-uk.org
Disclosures for purposes related to health and social care, including research

Consent

100 You should ask for consent to disclose personal information for purposes other than direct care unless the information is required by law, or it is not appropriate or practicable to obtain consent (see paragraph 19 for examples of when this might be the case).

Clinical audit

101 All doctors in clinical practice have a duty to participate in clinical audit and to contribute to clinical outcome review programmes. If an audit will be carried out by the team that provided care, or those working to support them, such as clinical audit staff, you may disclose personal information on the basis of implied consent, as long as you are satisfied that it is not practicable to use anonymised information and that the patient:

a has ready access to information that explains that their personal information may be disclosed for local clinical audit, and they have the right to object

b has not objected.

102 If a patient does object, you should explain why the information is needed and how this may benefit their own and others’ care. If the patient still objects, you should remove them from the audit if practicable. If that is not practicable you should make sure this is explained to the patient, along with the options open to them.

103 If a clinical audit will be carried out, but not by the team that provided care or those who support them, the information should be anonymised. If this is not practicable, or if personal information is essential to the audit, you should disclose the information only if you have the patient’s explicit consent or if there is another legal basis for breaching confidentiality (see paragraph 85). You must also be satisfied that the other relevant requirements for disclosing information are met (see paragraph 15).
Disclosures for financial or administrative purposes

104 If you are asked to disclose information about patients for financial or administrative purposes, you should give it in an anonymised form, if that is practicable and will serve the purpose. If identifiable information is needed, you must be satisfied that there is a legal basis for breaching confidentiality (see paragraph 85). You must also be satisfied that the other relevant requirements for disclosing information are met (see paragraph 15).

The professional duty of candour and confidentiality

105 All doctors have a duty of candour – a professional responsibility to be honest with patients when things go wrong. As part of this duty, doctors must tell the patient when something has gone wrong, and explain the short- and long-term effects of what has happened.

106 If the patient has died, or is unlikely to regain consciousness or capacity, it may be appropriate to speak to those close to the patient. When providing information for these purposes, you should still respect the patient’s confidentiality. If a patient has previously asked you not to share personal information about their condition or treatment with those close to them, you should abide by their wishes. You must still do your best to be considerate, sensitive and responsive to those close to the patient, giving them as much information as you can.

Being open about, and learning from, adverse incidents and near misses

107 A number of reporting systems and schemes exist around the UK for reporting adverse incidents and near misses. Organisations also have policies for reporting and responding to adverse incidents and near misses and in some cases organisational duties of candour have been written into law. If the law requires personal information to be disclosed for these purposes, you should follow the guidance in paragraph 92. If the law does not require it, you should ask for consent to disclose personal information.
unless it is not appropriate or practicable to do so (see paragraph 19). In exceptional cases, disclosure may be justified without consent in the public interest (see paragraphs 111–117).

Disclosures for health and social care purposes with statutory support

108 In England, Wales and Northern Ireland, statutory arrangements are in place for considering whether disclosing personal information without consent for health and social care purposes would benefit patients or the public sufficiently to outweigh patients’ right to privacy. Examples of these purposes include medical research, or the management of health or social care services.

109 Section 251 of the National Health Service Act 2006 (which applies in England and Wales) and the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 allow the common law duty of confidentiality to be set aside for defined purposes where it is not possible to use anonymised information and where seeking consent is not practicable. You can find more detail about these statutory arrangements in the legal annex. There is no comparable statutory framework in Scotland.

110 You may disclose personal information without consent if the disclosure is permitted or has been approved under regulations made under section 251 of the National Health Service Act 2006 or under the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016. If you know that a patient has objected to information being disclosed for purposes other than direct care, you should not usually disclose the information unless it is required under the regulations.40

Disclosures for health and social care purposes in the public interest

111 In exceptional circumstances, there may be an overriding public interest in disclosing personal information without consent for important health and social care purposes if there is no reasonably practicable alternative to using personal information and it is not practicable to seek consent. The benefits to society arising from the
Disclosure must outweigh the public and patients’ interest in keeping the information confidential.

112 You should not disclose personal information without consent in the public interest if the disclosure falls within the scope of any of the regulations described in paragraphs 108–110, and the disclosure is not permitted, or has not been approved, under those regulations.

113 If the regulations described in paragraphs 108–110 do not apply, you may need to make your own decision about whether disclosure of personal information without consent is justified. The circumstances in which the public interest would justify such disclosures are uncertain, however, so you should seek the advice of a Caldicott or data guardian or a legal adviser who is not directly connected with the use for which the disclosure is being considered before making the disclosure.  

114 Before considering whether disclosing personal information without consent may be justified in the public interest, you must satisfy yourself that it is either necessary to use identifiable information or not reasonably practicable to anonymise the information. In either case, you must be satisfied that it is not reasonably practicable to seek consent.

115 When considering whether disclosing personal information without consent may be justified in the public interest, you must take account of the factors set out in paragraph 72. You must also be satisfied that:

a the disclosure would comply with the requirements of data protection law and would not breach any other legislation that prevents the disclosure of information about patient (see the legal annex for examples)

b the disclosure is the minimum necessary for the purpose

c the information will be processed in a secure and controlled environment that has the capabilities and is otherwise suitable to process the information (see paragraph 91)
information is readily available to patients about any data that has been disclosed without consent, who it has been disclosed to, and the purpose of the disclosure.

116 If you know that a patient has objected to information being disclosed for purposes other than direct care, you should not disclose information in the public interest unless failure to do so would leave others at risk of death or serious harm (see paragraphs 68–75).

117 You must keep a record of what information you disclosed, your reasons, and any advice you sought.

**Ethical approval for research**

118 You should only disclose personal information for research if there is a legal basis for the disclosure and the research has been approved by a research ethics committee.

119 If you are applying for ethical approval for research, you should let the research ethics committee know if personal information will be disclosed without consent and tell them the legal basis for the disclosure.

**Requests for information from employers, insurers, government bodies and others**

120 Third parties, such as a patient’s insurer or employer, or a government department, or an agency assessing a claimant’s entitlement to benefits, may ask you for personal information about a patient, either following an examination or from existing records. In these cases, you should:

a be satisfied that the patient has sufficient information about the scope, purpose and likely consequences of the examination and disclosure, and the fact that relevant information cannot be concealed or withheld

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. You may accept an
assurance from an officer of a government department or agency, or a registered health professional acting on their behalf, that the patient or a person properly authorised to act on their behalf has consented

c only disclose factual information you can substantiate, presented in an unbiased manner, which is relevant to the request. You should not usually disclose the whole record, although it may be relevant to some benefits paid by government departments and to other assessments of a patient’s entitlement to pensions or other health-related benefits

d offer to show your patient, or give them a copy of, any report you write about them for employment or insurance purposes before it is sent, unless:

i they have already indicated they do not wish to see it

ii disclosure would be likely to cause serious harm to the patient or anyone else

iii disclosure would be likely to reveal information about another person who does not consent

121 If a patient refuses or withdraws consent, or if it is not practicable to get their consent, you may still disclose information if it can be justified in the public interest (see paragraphs 68–75). You must disclose information if it is required by law (see paragraphs 92–99).
Managing and protecting personal information

Improper access and disclosure

122 Health and care records can include a wide range of material, including but not limited to:

- handwritten notes
- electronic records
- correspondence between health professionals
- visual and audio recordings
- laboratory reports
- communications with patients (including texts and emails).

123 Many improper disclosures of patient information are unintentional. Conversations in reception areas, at a patient’s bedside and in public places may be overheard. Notes and records may be seen by other patients, unauthorised staff, or the public if they are not managed securely. Patient details can be lost if handover lists are misplaced, or when patient notes are in transit.

124 You must make sure any personal information about patients that you hold or control is effectively protected at all times against improper access, disclosure or loss. You should not leave patients’ records, or other notes you make about patients, either on paper or on screen, unattended. You should not share passwords.

125 You must not access a patient’s personal information unless you have a legitimate reason to view it.

126 You should not share personal information about patients where you can be overheard, for example in a public place or in an internet chat forum. While there are some practice environments in which it may be difficult to avoid conversations with (or
about) patients being overheard by others, you should to try to minimise breaches of confidentiality and privacy as far as it is possible to do so.

Knowledge of information governance and raising concerns

127 You must develop and maintain an understanding of information governance that is appropriate to your role. You must be familiar with, and follow, the confidentiality, data protection and record management policies and procedures where you work and know where to get advice on these issues. This includes policies on the use of laptops and mobile devices.

128 You should be satisfied that any members of staff you manage are trained and understand their information governance responsibilities. If you are responsible for employment contracts, you must make sure they contain obligations to protect confidentiality and to process information in line with data protection law.

129 Unless you have a role in commissioning or managing systems, you are not expected to assess the security standards of large-scale computer systems provided for your use in the NHS or in other managed healthcare environments. If, however, you are concerned about the security of personal information in premises or systems provided for your use, or the adequacy of staff training on information governance, you should follow our advice in Raising and acting on concerns about patient safety.47

Processing information in line with the Data Protection Act 1998

130 The Data Protection Act 1998 sets out the responsibilities of data controllers48 when processing personal data, as well as a number of rights for individuals (known as data subjects). Detailed guidance is available on the website of the Information Commissioner’s Office (ICO).49 You can find a summary of the data protection principles in the legal annex of this guidance.

131 If you are a data controller, you must understand and meet your obligations under data protection law. This includes responsibilities to make sure patients’ personal
information that you hold is handled in ways that are transparent and in ways that patients would reasonably expect, and appropriate technical and organisational measures are in place to guard against data loss. You must also make sure information is readily available to patients that explains:

- who has access to information you hold that might identify them and for what purposes
- their options for restricting access to some or all of their records
- their rights to complain about how their information is processed, and how to make a complaint.

When deciding how to provide this information, you should take into account the ICO’s guidance on fair processing or privacy notices.50

**Records management and retention**

132 If you are responsible for managing patient records or other patient information, you must make sure the records you are responsible for are made, stored, transferred, protected and disposed of in line with data protection law and other relevant laws. You should make use of professional expertise when selecting and developing systems to record, access and send electronic data.51

133 You must make sure any other records you are responsible for, including financial, management or human resources records, or records relating to complaints, are kept securely and are clear, accurate and up to date.52 You should make sure administrative information, such as names and addresses, can be accessed separately from clinical information so that sensitive information is not displayed automatically.

134 The UK health departments publish guidance on how long health records should be kept and how they should be disposed of. You should follow the guidance, even if you do not work in the NHS.53
The rights of patients to access to their own records

135 Patients have a right to access to their own health records, subject to certain safeguards.\textsuperscript{54} You should respect, and help patients to exercise, their legal rights to have access to, or copies of, their health records. The Information Commissioner's Office gives guidance on what fees you may charge. You should also follow our guidance on fees in \textit{Financial and commercial arrangements and conflicts of interest}.

Communicating with patients

136 Wherever possible, you should communicate with patients in a format that suits them. For example, electronic communications – such as email or text messaging – can be convenient and can support effective communication between doctors and patients.

137 Most communication methods pose some risk of interception – for example, messages left on answering machines can be heard by others and emails can be insecure. You should take reasonable steps to make sure the communication methods you use are secure and that you meet patients' expectations about how they will receive information.\textsuperscript{55}

138 You must make sure that any clinical information or advice you give to patients is recorded in the patient’s health record.

Disclosing information after a patient has died

139 Your duty of confidentiality continues after a patient has died.\textsuperscript{56}

140 There are circumstances in which you must disclose relevant information about a patient who has died. For example:

- when disclosure is required by law
- to help a coroner, procurator fiscal or other similar officer with an inquest or fatal accident inquiry\textsuperscript{57}
when a person has a right of access to records under the Access to Health Records Act 1990 or the Access to Health Records (Northern Ireland) Order 1993, unless an exemption applies (see the legal annex)

when disclosure is necessary to meet a statutory duty of candour.\textsuperscript{58}

141 In other circumstances, whether and what personal information may be disclosed after a patient’s death will depend on the facts of the case. If the patient had asked for information to remain confidential, you should usually abide by their wishes. If you are unaware of any instructions from the patient, when you are considering requests for information you should take into account:

a whether disclosing information is likely to cause distress to, or be of benefit to, the patient’s partner or family\textsuperscript{59}

b whether the disclosure will also disclose information about the patient’s family or anyone else

c whether the information is already public knowledge or can be anonymised or de-identified

d the purpose of the disclosure.

142 Circumstances in which you should usually disclose relevant information about a patient who has died include:

- the disclosure is permitted or has been approved under a statutory process which sets aside the common law duty of confidentiality, unless you know the patient has objected (see paragraphs 108–110)
- when disclosure is justified in the public interest to protect others from a risk of death or serious harm
- for public health surveillance, in which case the information should be anonymised, unless that would defeat the purpose
- when a parent asks for information about the circumstances and causes of a child’s death
- when a someone close to an adult patient asks for information about the circumstances of that patient’s death, and you have no reason to believe the patient would have objected to such a disclosure
- when disclosure is necessary to meet a professional duty of candour (see paragraphs 105 and 106)
- when it is necessary to support the reporting or investigation of adverse incidents, complaints, for local clinical audit, or for clinical outcome review programmes.60

143 Archived records relating to deceased patients remain subject to a duty of confidentiality, although the potential for disclosing information about, or causing distress to, surviving relatives or damaging the public’s trust will diminish over time.61
Legal annex

There is no overarching law that governs the disclosure of confidential information. The common law and other laws that require or permit the disclosure of patient information interact in complex ways and it is not possible to decide whether a use or disclosure of patient information would be lawful by considering any aspect of the law in isolation.

This section sets out some of the key elements of the law that are relevant to the use and disclosure of patient information, but it is not comprehensive. It is also not intended to be a substitute for independent, up-to-date legal advice. If you are unsure about the legal basis for a request for information, you should ask for clarification from the person making the request and, if necessary, seek independent legal advice.

**Sources of legal rights to confidentiality, data protection and privacy**

**The common law**

Information acquired by doctors in their professional capacity will generally be confidential under the common law. This duty is derived from a series of court judgments, which have established the principle that information given or obtained in confidence should not be used or disclosed further except in certain circumstances. This means the doctor must not disclose confidential information, unless there is a legal basis for doing so.

It is generally accepted that the common law allows disclosure of confidential information if:

- the patient consents
- it is required by law, or in response to a court order
- it is justified in the public interest.

But the common law cannot be considered in isolation. Even if a disclosure of confidential information is permitted under the common law, the disclosure must still satisfy the requirements of data protection law.
**Data Protection Act 1998** (UK)

The *Data Protection Act 1998* regulates the processing of personal data about living individuals in the UK. It sets out the responsibilities of data controllers when processing personal data as well as a number of rights for individuals, including rights of access to their information. The Information Commissioner (ICO) is the authority responsible for upholding information rights in the UK. Detailed guidance on complying with the Act is available on the website of the [Information Commissioner’s Office](https://ico.org.uk).

ICO guidance defines personal data as:

'data which relate to a living individual who can be identified

a from those data, or

b from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller,

and includes any expression of opinion about the individual and any indication of the intentions of the data controller or any other person in respect of the individual.'

The guidance also says 'where the ability to identify an individual depends partly on the data held and partly on other information (not necessarily data), the data held will still be “personal data”'.

ICO guidance defines a data controller as ‘a person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed’. Individual doctors can be data controllers in their own right (for example, if they are partners in general practice, or hold data in relation to patients whom they treat privately) but in many cases the data controller will be the doctor’s employer.

The Act is based around eight data protection principles, which state that personal data must:

- be fairly and lawfully processed
- be processed for limited purposes and not in any manner incompatible with those purposes
- be adequate, relevant and not excessive
- be accurate and up to date
- not be kept for longer than is necessary
- be processed in line with the data subject’s rights
- be secure
- not be transferred to countries outside of the EEA without adequate protection.

The first principle of the Act states that data must be processed lawfully and fairly. This means:

- patients’ information must not be processed in a way that breaches either statute or common law. For example, disclosing information would be a breach of the common law duty of confidentiality, it would also be unlawful under the Act
- patients’ personal information must be handled in ways that are transparent and in ways they would reasonably expect.

One or more of the conditions for processing in Schedule 2 (for all personal data) and Schedule 3 (for sensitive personal data) to the Act must also be met for the processing to be fair and lawful.

In all cases where personal data is processed, at least one of the conditions set out in Schedule 2 must be met. The conditions most likely to be relevant in medical practice are that:

- the data subject has given consent (Schedule 2, paragraph 1)
- the processing is necessary because of a legal obligation that applies to the data controller (except an obligation imposed by a contract) (Schedule 2, paragraph 3)
- the processing is necessary to protect the vital interests of the data subject (Schedule 2, paragraph 4)
the processing is necessary for the exercise of functions of a public nature
exercised in the public interest (Schedule 2, paragraph 5d)

- the processing is necessary for the purposes of legitimate interests pursued
  by the data controller (Schedule 2, paragraph 6).

Where ‘sensitive personal data’ are being used, at least one of the conditions in Schedule
3 must also be met. Information on a patient’s health record is likely to be ‘sensitive
personal data’ for the purposes of the Act. The conditions most likely to be relevant in
medical practice are that:

- the data subject has given explicit consent (Schedule 3, paragraph 1)
- the processing is necessary to protect the vital interests of the data subject or
  another person in a case where consent cannot be obtained or has been
  unreasonably withheld (Schedule 3, paragraph 3)
- the processing is necessary for medical purposes where the processing is
  undertaken by a health professional or someone else who owes an equivalent
duty of confidence (Schedule 3, paragraph 8).

In addition, the Data Protection (Processing of Sensitive Personal Data) Order 2000 sets
out other conditions for processing sensitive personal data. These conditions allow data
processing that is ‘in the substantial public interest’ and necessary for carrying out certain
public functions – including preventing or detecting crime, and protecting the public
against malpractice or other seriously improper conduct (for example, through
investigation into a healthcare professional’s fitness to practise).

**Human Rights Act 1998** (UK)

The Human Rights Act 1998 incorporates the European Convention on Human Rights
(ECHR) into UK law. A person’s right to have their privacy respected is protected by Article
8 of the ECHR. This right is not absolute, and may be interfered with where the law
permits and where it is ‘necessary in a democratic society in the interests of national
security, public safety or the economic well-being of the country, for the prevention of
disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.’

Any interference with a person’s right to privacy must be a necessary and proportionate response to the situation. This means there must be a fair balancing of competing interests. These include:

- the potential damage caused to the individual whose privacy will be breached
- society’s interest in the provision of a confidential health service
- the public interest that will be achieved through breaching the individual’s privacy.

Relevant factors to take into account when considering a disclosure in the public interest are given in paragraphs 68–75, and 111–117 of this guidance.

Other ECHR rights that may be relevant to considerations about whether disclosing a patient’s personal information is necessary and proportionate include Article 2 (which protects the right to life), Article 3 (which prohibits torture or inhumane or degrading treatment or punishment) and potentially others. Such considerations are complex and you should seek legal advice if necessary.


These Acts give public access to information held by public authorities. Public authorities include government departments, local authorities, the NHS, state schools and police forces. The Acts do not give people access to their own personal information such as their health records. If a member of the public wants to see information that a public authority holds about them, they should make a subject access request under the Data Protection Act 1998. You can find guidance about the Freedom of Information Act 2000 on the website of the Information Commissioner’s Office: www.ico.org.uk/for-organisations/guide-to-freedom-of-information. Guidance about the Freedom of Information (Scotland) Act 2002 is available on the website of the Scottish Information Commissioner: www.itspublicknowledge.info/Law/Legislation.aspx.
**Computer Misuse Act 1990** (UK)

It is an offence under this Act to gain unauthorised access to computer material. This would include using another person’s ID and password without authority to use, alter or delete data.

**Regulation of healthcare providers and professionals**

Various bodies regulating healthcare providers and professionals have legal powers to require information to be disclosed, including personal information about patients. The following sets out only a selection of these bodies, and gives a summary of their most relevant powers and refers to the codes of practice they publish about how they use their powers.

The **Care Quality Commission** (CQC) in England has powers of inspection and entry and to require documents and information under the *Health and Social Care Act 2008*. Sections 76 to 79 govern the CQC’s use and disclosure of confidential personal information. Section 80 requires it to consult on and publish a code of practice on how it obtains, handles, uses and discloses confidential personal information. You can find the code of practice on the CQC’s website: www.cqc.org.uk/file/4201.

**Healthcare Inspectorate Wales** has powers under the *Health and Social Care (Community Health and Standards) Act 2003* to access a patient’s personal information.

**Healthcare Improvement Scotland** has similar powers in relation to registered independent healthcare providers under the *Public Services Reform (Scotland) Act 2010*.

The **Regulation and Quality Improvement Authority** in Northern Ireland has powers under sections 41 and 42 of the *Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003* to enter establishments and agencies and health and social services bodies or providers’ premises and inspect and take
copies of records, subject to the protection of confidential information provided for in section 43.

**NHS Protect** has powers under the *National Health Service Act 2006* and the *National Health Service (Wales) Act 2006* to require the production of documents to prevent, detect and prosecute fraud in the NHS. The Department of Health (England) and Welsh Assembly Government have published codes of practice for the use of these powers. There are no comparable specific powers to require the production of documents for these purposes in Scotland or Northern Ireland.

The **General Medical Council** has powers under section 35A of the *Medical Act 1983* (as amended) to require disclosure of information and documentation relevant to the discharge of our fitness to practise functions, provided such disclosure is not prohibited by other laws. Other professional regulators have similar powers. For example, the **Nursing and Midwifery Council** has powers to require disclosure of patient information for the purpose of carrying out its fitness to practise functions in some circumstances under section 25 of the *Nursing and Midwifery Order 2001*.

The **Parliamentary and Health Service Ombudsman**, the **Northern Ireland Public Service Ombudsman**, the **Public Services Ombudsman for Wales** and the **Scottish Public Services Ombudsman** have legal powers similar to the High Court or Court of Session to require the production of documents and the attendance and examination of witnesses for the purposes of investigations about the health bodies that fall within their remits.

**Laws that require or permit disclosures for health and social care purposes**

**Health and Social Care Act 2012** (England)

Section 259 gives the Health and Social Care Information Centre (known as NHS Digital) the power to require providers of health and social care in England to send it confidential data in limited circumstances, including when directed to do so by the Secretary of State.
for Health or NHS England. Patient consent is not needed, but patient objections will be handled in line with the pledges set out in the NHS Constitution and directions given to NHS Digital by the Secretary of State.

**Health and Social Care (Safety and Quality) Act 2015** (England)

This Act places a duty on providers and commissioners of health and social care in England to share information when it is considered likely to facilitate the provision of health or social care to an individual and when it is in the individual’s best interests. The duty will not apply where an individual objects (or would be likely to object), or where the information is connected with the provision of care by ‘an anonymous access provider’ (such as a sexual health service) or where the duty cannot be reasonably complied with for other reasons. The duty does not override duties under the common law or the Data Protection Act 1998. The Information Governance Alliance has published guides to the Health and Social Care (Safety and Quality) Act 2015 on its website: [http://systems.hscic.gov.uk/infogov/iga/resources/infosharing](http://systems.hscic.gov.uk/infogov/iga/resources/infosharing).

**Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016**

This Act requires the Department of Health in Northern Ireland to make regulations that permit or require the processing of confidential information for defined health and social care purposes. The Act allows the common law duty of confidentiality to be set aside where seeking individuals’ consent is not practicable, where it is not possible to use anonymised information and where the committee established under the Act has authorised the processing. The Act does not set aside the Data Protection Act 1998 or the Human Rights Act 1998 and any use of information must continue to comply with the requirements of these two pieces of legislation.

No regulations have yet been made under the Act. Until such regulations are made the Privacy Advisory Committee will continue to advise health and social care bodies about the use of information relating to patients and clients. You can find out more about the committee on its website: [www.privacyadvisorycommittee.hscni.net](http://www.privacyadvisorycommittee.hscni.net).
Section 251 of the NHS Act 2006 (England and Wales)

Section 251 of this Act allows the Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes. In practice, this means the person responsible for the information can disclose confidential patient information without consent to an applicant without being in breach of the common law duty of confidentiality, as long as the requirements of the regulations are met. The person responsible for the information must still comply with all other relevant legal obligations such as the Data Protection Act 1998 and the Human Rights Act 1998.

The regulations that enable this power are called the Health Service (Control of Patient Information) Regulations 2002. Any references to ‘section 251 support or approval’ actually refer to approval given under the authority of the regulations. These powers can only be used where it is not practical to obtain consent and anonymised information cannot be used, having regard to the cost and available technology. They cannot be used to permit information to be disclosed solely or principally for the direct care of individual patients. The regulations only apply in England and Wales.

The regulations provide different kinds of support.

- Regulation 2 provides specific support for cancer registries to receive and process identifiable data on patients referred for the diagnosis or treatment of cancer for the medical purposes set out in the regulation.
- Regulation 3 provides specific support for identifiable patient information to be disclosed to, and processed by, the persons or bodies listed in paragraph 3 of Regulation 3 when processing is intended to diagnose, control, prevent, or recognise trends in communicable diseases and other risks to public health.
- Regulation 5 can be used to permit processing for a range of medical purposes, broadly defined to include ‘preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of health and social care services’. Any person wishing to obtain support under Regulation 5 will submit an application to the Confidentiality Advisory Group of the Health Research Authority. The Confidentiality Advisory Group will then give advice to the relevant decision maker, which is currently the Health Research Authority for research
applications and the Secretary of State for Health for non-research applications. The Confidentiality Advisory Group will not usually authorise disclosures under regulation 5 to which the patient has objected. The Health Research Authority may not give an approval unless a research ethics committee has approved the medical research concerned.


**Other laws that require or permit disclosures**

**Access to patient records and disclosures of reports**


These pieces of legislation provide rights of access to a deceased patient’s personal representative and any person who may have a claim arising out of a patient’s death. This is not a general right, however, and access should be limited to information of relevance to the claim. Access should be limited or refused if there is evidence that the patient would have expected that the information would not be disclosed to the applicant, if disclosure is likely to cause serious harm to anyone else, or if it would also disclose information about a third party (other than a healthcare professional involved in the deceased person’s care) who does not consent. Access must be refused to records that contain a note, made at the patient’s request, expressing that they did not wish access to be given on an application under the Act. These Acts only give access to records created on or after the date on which they came into force (November 1991 for England, Scotland and Wales; 30 May 1994 for Northern Ireland). Access must also be given to information recorded before these dates if this is necessary to make any later part of the records intelligible.

*Access to Medical Reports Act 1988* (England, Scotland and Wales) and *Access to Personal Files and Medical Reports (Northern Ireland) Order 1991*. 

www.gmc-uk.org
These pieces of legislation give patients the right to see medical reports written about them, for employment or insurance purposes, by a doctor who is or has been responsible for the clinical care of the individual. This includes the right to see reports written by the patient’s GP or by a specialist who has provided care. Patients have the right to ask the doctor to amend any part of the report that the patient considers to be incorrect or misleading, and to attach their disagreement to the report, or to withdraw their consent for the release of the information.

**Adult safeguarding and support**

**Adult Support and Protection (Scotland) Act 2007.**

This Act requires health boards in Scotland to report to local authorities if they know or believe an adult is at risk of harm (whether or not they lack capacity to make the decision) and action needs to be taken to protect them. The Act also requires certain public bodies and office-holders to cooperate with local authorities making enquiries about adults at risk and includes powers to examine health records for related purposes. You can read detailed guidance in the *Adult Support and Protection Code of Practice*, available at [www.gov.scot/Publications/2014/05/6492](http://www.gov.scot/Publications/2014/05/6492).

**Care Act 2014** (England)

This Act requires ‘relevant partners’ to cooperate with local authorities making enquiries about adults at risk unless an exemption set out in the Act applies. Relevant partners include NHS trusts, foundation trusts and clinical commissioning groups in the local authority’s area. Certain persons or bodies must also give information to safeguarding adults boards, if they ask for the information to enable or assist the board to perform its functions. The explanatory notes to the Act make clear that individual doctors can be asked for information under this provision. You can read detailed guidance in the Care and Support Statutory Guidance, available at [www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation](http://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation).

**Carers (Scotland) Act 2016**

This Act places duties on local authorities to seek and take account of the views of carers when determining a cared for person’s needs. It also placed a duty on health boards to
share information with carers about a cared for person who is being discharged from hospital and to seek the views of the carers about the discharge and take account of those views. The Act is expected to come into force in 2017–18.

**Social Services and Well-being (Wales) Act 2014**

This Act requires ‘relevant partners’ (which include local health boards and NHS trusts in Wales) to tell local authorities if they have reasonable cause to suspect an adult is at risk of harm (whether or not they lack capacity to make the decision). The Act also requires relevant partners to cooperate with local authorities making enquiries about adults at risk, and certain persons or bodies to give information to adults safeguarding boards, unless an exemption set out in the Act applies.

**Mental capacity and mental health legislation**

*Adults with Incapacity (Scotland) Act 2000 and Mental Capacity Act 2005* (England and Wales).

These pieces of legislation provide for information to be shared with anyone who is authorised to make decisions on behalf of, or who is appointed to support and represent, a patient who lacks capacity. This might be a welfare attorney, a court-appointed deputy or guardian or an independent mental capacity advocate. You can read detailed guidance in the *Adults with Incapacity (Scotland) Act 2000* codes of practice, available at www.gov.scot/Topics/Justice/law/awi/010408awiwebpubs/com and in the *Mental Capacity Act Code of Practice*, available at www.gov.uk/government/publications/mental-capacity-act-code-of-practice. The main provisions of the *Mental Capacity Act (Northern Ireland) 2016* have not yet come into force.

*Mental Health Act 1983, Mental Health (Care and Treatment) (Scotland) Act 2003 and Mental Health Northern Ireland Order (1986).* These pieces of legislation provide for a number of situations in which confidential information about patients can be disclosed, even if the patient does not consent. You can find detailed guidance in the *Mental Health Act 1983: Code of Practice*, available at www.gov.uk/government/publications/code-of-practice-mental-health-act-1983; in the *Code of Practice* under the *Mental Health (Care & Treatment) (Scotland) Act 2003*,...

Public health and other mandatory notification schemes

*Abortion Regulations 1991* (England and Wales) and *Abortion (Scotland) Regulations 1991*. A doctor who has carried out a termination of pregnancy must notify the appropriate chief medical officer of that fact within seven days of the termination. There is no equivalent legislation in Northern Ireland.

*The Controlled Drugs (Supervision of Management and Use) Regulations 2013 (England and Scotland); The Controlled Drugs (Supervision of Management and Use) Regulations (Northern Ireland) 2009* (as amended) and *The Controlled Drugs (Supervision of Management and Use) (Wales) Regulations 2008*

Under these regulations, responsible bodies are required to cooperate with each other in relation to the handling of, and acting on, shared information relating to the management and use of controlled drugs. As far as possible, information that identifies patients should be removed before disclosure, but it may be necessary for identifiable information to be disclosed in some circumstances, with consent if practicable. Further guidance is provided by the UK Department of Health for the regulations in England and Scotland: www.gov.uk/government/uploads/system/uploads/attachment_data/file/214915/15-02-2013-controlled-drugs-regulation-information.pdf; by the Department of Health Northern Ireland: www.health-ni.gov.uk/publications/guidance-safe-management-and-use-controlled-drugs; and by Healthcare Inspectorate Wales: www.hiw.org.uk/controlled-drugs.

Registered doctors in each of the UK countries have statutory duties to notify an appropriate person or body of suspected cases of certain infectious diseases. In England, Scotland and Wales, doctors must also notify cases of other infections or of contamination which they believe present, or could present, a significant risk to human health. Detailed guidance has been published by Public Health England: www.gov.uk/government/collections/notifications-of-infectious-diseases-noids#guidance; the Scottish Government: www.gov.scot/Topics/Health/Policy/Public-Health-Act/Implementation/Guidance/Guidance-Part2; the Department of Health in Northern Ireland: www.infectioncontrolmanual.co.ni/; and NHS Wales: www.gov.wales/docs/phhs/publications/100716ahealthprotguidanceen.pdf.

**Prevention, detection and prosecution of crime**

**Crime and Disorder Act 1998 (UK)**

Section 115 permits disclosure to organisations such as the police, local authorities, or probation services but does not create a legal obligation to do so. Information should only be disclosed if the patient consents, or there is an overriding public interest, or in response to a court order.

**Criminal Law Act (Northern Ireland) 1967**

Section 5 places a duty on all citizens to report to the police information they may have about the commission of a relevant offence (one with a maximum sentence of five years or more). The duty does not arise where a person has a ‘reasonable excuse’ not to disclose the information.

**Road Traffic Act 1988** (England, Scotland and Wales) and **Road Traffic (Northern Ireland Order) 1981**

In certain circumstances, all citizens (including doctors) must give the police, on request, any information that may identify a driver alleged to have committed a traffic offence.

**Terrorism Act 2000 (UK)**
Under section 38B of this Act, it is a criminal offence for a person to fail to disclose information to the police that they know or believe might be relevant in preventing an act of terrorism or securing the arrest, prosecution or conviction of a person for a terrorist act. Even if the threshold for a disclosure required by law isn’t met, disclosure may still be justified in the public interest if there are clear grounds for believing that it will protect a specific person or people – or the public more broadly – from risk of death or serious harm. The Department of Health has issued guidance on the ‘prevent duty’ for healthcare professionals that sets out the types of behaviour doctors should be aware of. The advice reassures doctors that they are not expected to take on a surveillance role, but sets out the sorts of steps they might take if they are concerned that a patient may be involved in, or at risk of being drawn into, terrorist-related activity. You can find it at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/215253/dh_131912.pdf.

**Statutory restrictions on disclosing information about patients**

**Gender Recognition Act 2004** (UK)

Section 22 of the Act makes it an offence to disclose ‘protected information’ when that information is acquired in an official capacity. ‘Protected information’ is defined as information about a person’s application for gender recognition and a person’s gender history after that person has changed gender under the Act. Section 22 also sets out a series of exceptions, where disclosure is considered to be justified. These are further expanded and clarified by The Gender Recognition (Disclosure of Information) (England, Wales and Northern Ireland) Order 2005 and The Gender Recognition (Disclosure of Information) (Scotland) Order 2005.

**Human Fertilisation and Embryology Act 1990** (UK).

Section 33A protects the confidentiality of information kept by clinics and the Human Fertilisation and Embryology Authority (HFEA). Information may be accessed or disclosed only in the specific circumstances set out in the Act. Disclosing information that identifies the patient in other circumstances without the patient’s prior consent is a criminal offence.
The National Health Service (Venereal Diseases) Regulations 1974 and the NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000. These regulations provide that any information capable of identifying an individual who is examined or treated for any sexually transmitted disease including HIV shall not be disclosed, other than to a medical practitioner in connection with the treatment of the individual or for the prevention of the spread of the disease.
The Caldicott Principles

1 **Justify the purpose(s).** Every proposed use or transfer of personal confidential data within or from an organisation should be clearly defined, scrutinised and documented, with continuing uses regularly reviewed, by an appropriate guardian.

2 **Don’t use personal confidential data unless it is absolutely necessary.**
   Personal confidential data items should not be included unless it is essential for the specified purpose(s) of that flow. The need for patients to be identified should be considered at each stage of satisfying the purpose(s).

3 **Use the minimum necessary personal confidential data.** Where use of personal confidential data is considered to be essential, the inclusion of each individual item of data should be considered and justified so that the minimum amount of personal confidential data is transferred or accessible as is necessary for a given function to be carried out.

4 **Access to personal confidential data should be on a strict need-to-know basis.** Only those individuals who need access to personal confidential data should have access to it, and they should only have access to the data items that they need to see. This may mean introducing access controls or splitting data flows where one data flow is used for several purposes.

5 **Everyone with access to personal confidential data should be aware of their responsibilities.** Action should be taken to ensure that those handling personal confidential data — both clinical and non-clinical staff — are made fully aware of their responsibilities and obligations to respect patient confidentiality.

6 **Comply with the law.** Every use of personal confidential data must be lawful. Someone in each organisation handling personal confidential data should be responsible for ensuring that the organisation complies with legal requirements.

7 **The duty to share information can be as important as the duty to protect patient confidentiality.** Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies.
Endnotes

1 Caldicott or data guardians are senior people in the NHS, local authority social care services, and partner organisations, who are responsible for protecting the confidentiality of patient information and enabling appropriate information sharing.

2 In this guidance, ‘personal information’ means information from which individuals can be identified either in itself or in combination with other available information. ‘Disclosure’ means the provision or passing of information about a patient to anyone other than the patient, regardless of the purpose. Sharing information within healthcare teams is a form of disclosure, as is providing access to patients’ records.

3 These principles are aligned with the Caldicott principles, which are reproduced in this guidance on page xx.

4 We use the term ‘overall benefit’ to describe the ethical basis on which decisions are made about treatment and care for adult patients who lack capacity to decide. Our guidance on overall benefit is consistent with the legal requirement to consider whether treatment ‘benefits’ a patient (as the term is used in the Adults with Incapacity (Scotland) Act 2000), or is in the patient's ‘best interests’ (as the term is used in the Mental Capacity Act 2005 in England and Wales, and in the common law in Northern Ireland. The use of the term is also consistent with the legal requirement to apply the other principles set out in the Mental Capacity Act 2005 and Adults with Incapacity (Scotland) Act 2000.

5 Doctors working in a managed environment will do this largely by understanding and following this guidance and corporate information governance and confidentiality policies. Doctors who are themselves data controllers are personally responsible for understanding and meeting their responsibilities under the Data Protection Act 1998. See the legal annex to this guidance for more information.

6 We give detailed advice on consent in our guidance Consent: doctors and patients making decisions together (General Medical Council, 2008). You can find all GMC guidance on professional standards and ethics at www.gmc-uk.org/guidance.

7 See paragraphs 26 and 27 of our guidance Consent (referenced in endnote 6). See also paragraph 120 of this guidance.

8 In 2013, the Caldicott principles were updated to include a new principle: ‘the duty to share information can be as important as the duty to protect patient confidentiality.’ The full list of Caldicott principles is given on page xx.

9 Direct care refers to activities that directly contribute to the diagnosis, care and treatment of an individual. The direct care team is made up of those health and social care professionals who provide direct care to the patient and others, such as administrative staff, who directly support that care.

10 In England the Health and Social Care (Safety and Quality) Act 2015 created a duty to share information for direct care except in certain circumstances. See the legal annex to this guidance for more information.

11 For example, if staff providing treatment may be at risk of serious harm which cannot be managed through the use of universal precautions. See our explanatory guidance Disclosing information about serious
communicable diseases. You can find all GMC guidance on professional standards and ethics at www.gmc-uk.org/guidance.

12 Patients are also entitled to access their health records under the Data Protection Act 1998. See endnote 54.

13 See the Adults with Incapacity (Scotland) Act 2000 and the Mental Capacity Act 2005 and their respective codes of practice. The main provisions of the Mental Capacity Act (Northern Ireland) 2016 have not yet come into force. The common law duty to act in the best interests of a patient who lacks capacity to consent therefore continues until the Act is commenced.

14 Independent mental health advocates should also be given the information listed in section 130B of the Mental Health Act 1983. Guidance on the roles of independent mental health advocates is given in the Mental Health Act 1983 Code of Practice 2015.

15 See the Adults with Incapacity (Scotland) Act 2000 and the Mental Capacity Act 2005 and their respective codes of practice. The main provisions of the Mental Capacity Act (Northern Ireland) 2016 have not yet come into force. The common law duty to act in the best interests of a patient who lacks capacity to consent therefore continues until the Act is commenced.

16 Independent mental health advocates should also be given the information listed in section 130B of the Mental Health Act 1983. Guidance on the roles of independent mental health advocates is given in the Mental Health Act 1983 Code of Practice 2015.

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crime. These include crimes that cause serious physical or psychological harm to individuals (such as murder, manslaughter, rape and child abuse); serious harm to the security of the state and public order and ‘crimes that involve substantial financial gain or loss’ are also mentioned in the same category. It also gives examples of crimes that are not usually serious enough to warrant disclosure without consent (including theft, fraud, and damage to property where loss or damage is less substantial). The guidance is available at www.gov.uk/government/uploads/system/uploads/attachment_data/file/200147/Confidentiality_-_NHS_Code_of_Practice_Supplementary_Guidance_on_Public_Interest_Disclosures.pdf. **Guidance for NHS staff on reporting crime**

23 We give specific advice on reporting concerns about patients’ fitness to drive in our explanatory guidance *Confidentiality: Patients’ fitness to drive and reporting concerns to the DVLA or DVA*. That guidance deals specifically with drivers on the roads, but the same principles apply to drivers and pilots of other kinds of regulated transport, including by rail, water and air. You can find all GMC guidance on professional standards and ethics at www.gmc-uk.org/guidance.

24 See our explanatory guidance *Confidentiality: disclosing information about serious communicable diseases*. See endnote 23 for the web address.

25 See our explanatory guidance *Confidentiality: disclosing information for employment, insurance and similar purposes*. See endnote 23 for the web address.

26 You should consider the assessment of risk posed by patients made by other professionals and by groups established for that purpose, but you must make your own assessment and decision as to whether disclosure is justified. Your assessment of risk is a matter of professional judgement in which an offender’s past behaviour will be a factor. The Royal College of Psychiatrists publishes guidance for psychiatrists about sharing information in the context of public protection, including participation in multi-agency public protection arrangements (MAPPA) and panels. The guidance is available at www.rcpsych.ac.uk/files/pdfversion/CR160.pdf.

27 For more information, see *Consent and confidentiality in clinical genetic practice: Guidance on genetic testing and sharing genetic information – A report of the Joint Committee on Medical Genetics* (Royal College of Physicians, second edition, 2011). The guidance is available at www.bsgm.org.uk/media/678746/consent_and_confidentiality_2011.pdf.

28 See endnote 2 for the definition of ‘personal information’ in this guidance.


30 Other potential identifiers include the patient’s initials, postcode, NHS or CHC number, local identifiers (such as hospital numbers), national insurance number, and key dates (such as birthdate, date of diagnosis or date of death).

31 See endnote 29 for the reference to ICO guidance.

32 The *NHS Constitution* in England and NHS Scotland’s *The Charter of Patient Rights and Responsibilities* both set out the rights of a patient to object to how their information is used. Under the *Data Protection Act*...
1998, a data subject has a right to object to processing if it causes unwarranted and substantial damage or distress. For more information, see the Guide to Data Protection on the website of the Information Commissioner’s Office: www.ico.org.uk/for-organisations/guide-to-data-protection.


34 See endnote 9 for the definition of ‘direct care’ in this guidance. Guidance on sharing information for direct care purposes is given in paragraphs 31–38.

35 In this guidance ‘clinical audit’ means the evaluation of clinical performance against standards or through comparative analysis, to inform the management of services.

36 See Good medical practice (2013), paragraph 22. You can find all GMC guidance on professional standards and ethics at www.gmc-uk.org/guidance. Formerly known as national confidential inquiries, clinical outcome review programmes are systematic reviews that are carried out with the aim of supporting changes that can help improve the quality and safety of healthcare delivery. You can find more information on the website of the Healthcare Quality Improvement Partnership: www.hqip.org.uk.

37 Commissioners have limited rights to request personal information held by general practices for defined purposes, although they should usually respect patients’ objections. See the directions on confidentiality and disclosure of information and the code of practice for the relevant country for more information. Confidentiality and Disclosure of Information (General Medical Services, Personal Medical Services, Alternative Provider Medical Services) Directions 2013 and Code of Practice (Department of Health, 2013); Confidentiality and Disclosure of Information: General Medical Services and Alternative Provider Medical Services Directions (Northern Ireland) 2006 and Code of Practice (Department of Health, Social Services and Public Safety, 2006); Confidentiality and Disclosure of Information: General Medical Services (GMS), Section 17c Agreements, and Health Board Primary Medical Services (HBPMS) Directions 2005 and Code of Practice (Scottish Executive Health Department, 2005); Confidentiality and Disclosure of Information: General Medical Services and Alternative Provider Medical Services Directions 2006 and Code of Practice (Welsh Assembly Government, 2005).

38 We give guidance on professional and organisational duties of candour in Openness and honesty when things go wrong: the professional duty of candour (General Medical Council and Nursing and Midwifery Council, 2015). You can find all GMC guidance on professional standards and ethics at www.gmc-uk.org/guidance.

39 The obligations associated with the statutory duty of candour in England are contained in regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. In Scotland they are contained in section 22 of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016.

40 Disclosures permitted under regulations 2 and 3 of the Health Service (Control of Patient Information) Regulations 2002 may, in some circumstances, be required rather than permitted. The Confidentiality Advisory Group of the Health Research Authority will not usually authorise disclosures under regulation 5 to which the patient has objected. See the legal annex for more detail on the regulations.
41 In Scotland, the Public Benefit and Privacy Panel for Health and Social Care scrutinises requests for access to some (but not all) NHSScotland originated data. You may disclose personal information if the disclosure has been approved by the Public Benefit and Privacy Panel for Health and Social Care.

42 The Confidentiality Advisory Group of the Health Research Authority has published a document which clarifies how the group interprets the term ‘reasonably practicable alternative’ to using confidential information without consent, which you may find helpful. It is available at www.hra.nhs.uk/documents/2014/12/principles-advice-april-2013-v-2.pdf.

43 Disclosure of the whole record may breach the principles of the Data Protection Act 1998, as the full record may contain information that is excessive and not relevant for the purpose.

44 If any of the exceptions set out in paragraph 120(d) of this guidance apply, you should still disclose as much of the report as you can. The Department for Work and Pensions publishes advice about reports for benefits purposes: www.gov.uk/government/collections/healthcare-practitioners-guidance-and-information-from-dwp.

45 In some circumstances, patients are entitled to see a report that has been written about them under the provisions of the Access to Medical Reports Act 1988. See the legal annex to this guidance for more details.

46 See also our guidance Doctors’ use of social media (General Medical Council, 2013). You can find all GMC guidance on professional standards and ethics at www.gmc-uk.org/guidance.

47 Raising and acting on concerns about patient safety (General Medical Council, 2012). See endnote 46 for the web address.

48 The Act defines a ‘data controller’ as a person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed. Key definitions of terms in the Data Protection Act 1998 are available on the website of the Information Commissioner’s Office, at www.ico.org.uk/for-organisations/guide-to-data-protection/key-definitions.


50 This is contained in the Guide to data protection; see endnote 49.

51 The Information Commissioner’s Office publishes technical guidance. The Health and Social Care Information Centre in England publishes good practice guidelines on technology-specific areas of information security and information governance: http://systems.hscic.gov.uk/infogov/security/infrasec/gpg. It also publishes the Information Governance Toolkit for NHS organisations, which is an online system that allows NHS organisations and partners to assess themselves against Department of Health Information Governance policies and standards: www.igt.hscic.gov.uk. In Scotland, guidance and information governance standards are collected on the Knowledge Network: www.knowledge.scot.nhs.uk/ig.aspx. In Wales, organisations are expected to use the online Caldicott-Principles Into Practice (C-PIP) assessment to measure their compliance with components of information security: www.wales.nhs.uk/sites3/home.cfm?orgid=950. GPs are required to assess their compliance with the


54 Section 7 of the *Data Protection Act 1998* gives patients the right to access their personal information, although exemptions apply in certain circumstances. For example, an exemption applies if providing subject access to information about an individual’s physical or mental health or condition would be likely to cause serious harm to them or to another person’s physical or mental health or condition. You also do not have to supply a patient with information about another person or that identifies another person as the source of the information, unless that other person consents or it is reasonable in the circumstances to supply the information without their consent. See the Information Commissioner’s technical guidance, *Dealing with subject access requests involving other people’s information*. The guidance is available at [www.ico.org.uk/media/for-organisations/documents/1065/subject-access-code-of-practice.pdf](http://www.ico.org.uk/media/for-organisations/documents/1065/subject-access-code-of-practice.pdf).


56 There is an obvious ethical obligation. There may also be a legal obligation: see *Lewis v. Secretary of State for Health* [2008] EWHC 2196. Section 38 of the *Freedom of Information (Scotland) Act 2002* includes a deceased person’s medical records within the definition of personal information, which is exempt from the general entitlement to information.

57 See paragraph 73 of *Good medical practice* (General Medical Council, 2013) and paragraph 22 of our explanatory guidance *Acting as a witness in legal proceedings* (General Medical Council, 2013). You can find all GMC guidance on professional standards and ethics at [www.gmc-uk.org/guidance](http://www.gmc-uk.org/guidance).

58 See endnote 39.
The permission of a surviving relative or next of kin is not required for, and does not authorise, disclosure of confidential information, although the views of those who were close to the patient may help you decide if disclosure is appropriate.

See endnote 36 for a description of clinical outcome review programmes.

You should contact your organisation’s approved place of deposit or The National Archives, the Public Record Office of Northern Ireland or the National Archives for Scotland for further advice about storage of, and access to, archives of records of ongoing research or historical value. Health records of deceased patients are exempt from the Freedom of Information (Scotland) Act 2002.
6 - Confidentiality guidance

Confidentiality: patients’ fitness to drive and reporting concerns to the DVLA or DVA
Confidentiality: patients’ fitness to drive and reporting concerns to the DVLA or DVA

In our guidance *Confidentiality* we say:

7 Trust is an essential part of the doctor-patient relationship and confidentiality is central to this. Patients may avoid seeking medical help, or may under-report symptoms, if they think that their personal information will be disclosed by doctors without consent, or without the chance to have some control over the timing or amount of information shared.

65 Doctors owe a duty of confidentiality to their patients, but they also have a wider duty to protect and promote the health of patients and the public.

67 You should ask for a patient’s consent to disclose information for the protection of others unless it is not safe or practicable to do so,¹ or the information is required by law. You should consider any reasons given for refusal.

69 If it is not practicable to seek consent, and in exceptional cases where a patient has refused consent, disclosing personal information may be justified in the public interest if failure to do so may expose others to a risk of death or serious harm. The benefits to an individual or to society of the disclosure must outweigh both the public and the patient’s interest in keeping the information confidential.

73 If you consider that failure to disclose the information would leave individuals or society exposed to a risk so serious that it outweighs the patient’s and the public interest in maintaining confidentiality, you should disclose relevant information promptly to an appropriate person or authority. You should inform the patient before disclosing the information, if it is
practicable and safe to do so, even if you intend to disclose without their consent.

About this guidance
2 Doctors owe a duty of confidentiality to their patients, but they also have a wider duty to protect and promote the health of patients and the public. This explanatory guidance sets out the steps doctors should take if a patient’s failure or refusal to stop driving exposes others to a risk of death or serious harm.

Fitness to drive: doctors’ and patients’ responsibilities
3 The Driver and Vehicle and Licensing Agency (DVLA) in England, Scotland and Wales and the Driver and Vehicle Agency (DVA) in Northern Ireland are legally responsible for deciding if a person is medically unfit to drive. This means they need to know if a person holding a driving licence has a condition or is undergoing treatment that may now, or in the future, affect their safety as a driver.

4 The driver is legally responsible for telling the DVLA or DVA about any such condition or treatment. Doctors should therefore alert patients to conditions and treatments that might affect their ability to drive and remind them of their duty to tell the appropriate agency. Doctors may, however, need to make a decision about whether to disclose relevant information without consent to the DVLA or DVA in the public interest if a patient is unfit to drive but continues to do so.

Assessing a patient’s fitness to drive
5 When diagnosing a patient’s condition, or providing or arranging treatment, you should consider whether the condition or treatment may affect their ability to drive safely. You should:

- refer to the DVLA’s guidance *Assessing fitness to drive – a guide for medical professionals*, which includes information about disorders and conditions that can impair a patient’s fitness to drive
- seek the advice of an experienced colleague or the DVLA’s or DVA’s medical adviser if you are not sure whether a condition or treatment might affect a patient’s fitness to drive.
Reporting concerns to the DVLA or DVA

6 If a patient has a condition or is undergoing treatment that could impair their fitness to drive, you should:

   a explain this to the patient and tell them that they have a legal duty to inform the DVLA or DVA

   b tell the patient that you may be obliged to disclose relevant medical information about them, in confidence, to the DVLA or DVA if they continue to drive when they are not fit to do so

   c make a note of any advice you have given to a patient about their fitness to drive in their medical record.

7 If a patient is incapable of understanding this advice – for example, because of dementia – you should inform the DVLA or DVA as soon as practicable.

8 If a patient refuses to accept the diagnosis, or the effect of the condition or treatment on their ability to drive, you can suggest that they seek a second opinion, and help arrange for them to do so. You should advise the patient not to drive in the meantime. As long as the patient agrees, you may discuss your concerns with their relatives, friends or carers.

9 If you become aware that a patient is continuing to drive when they may not be fit to do so, you should make every reasonable effort to persuade them to stop. If you do not manage to persuade the patient to stop driving, or you discover that they are continuing to drive against your advice, you should consider whether the patient’s refusal to stop driving leaves others exposed to a risk of death or serious harm. If you believe that it does, you should contact the DVLA or DVA promptly and disclose any relevant medical information, in confidence, to the medical adviser.

10 Before contacting the DVLA or DVA, you should try to inform the patient of your intention to disclose personal information. If the patient objects to the disclosure, you should consider any reasons they give for objecting. If you decide to contact the DVLA
or DVA you should tell your patient in writing once you have done so, and make a note on the patient’s record.

**Responding to requests for information from the DVLA or the DVA**

11 If you agree to prepare a report or complete or sign a document to assist the DVLA’s or the DVA’s assessment of a patient’s fitness to drive, you should do so without unreasonable delay.

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**Endnotes**

1 We give examples of when it might not be practicable to seek consent in paragraph 19 of *Confidentiality*. You can find all of our guidance online at [www.gmc-uk.org/guidance](http://www.gmc-uk.org/guidance).

2 See ’The duties of a doctor registered with the General Medical Council’ in *Good medical practice*, which you can find at [www.gmc-uk.org/guidance](http://www.gmc-uk.org/guidance).

3 The principles in this guidance also apply to drivers and pilots of other kinds of regulated transport, including by rail, water and air, although such individuals are likely to undergo medical assessment as part of the relevant licensing or certificating process. If you are concerned that a patient who holds a private or commercial pilot licence may be medically unfit to fly an aircraft, you can contact the UK Civil Aviation Authority’s medical department on 01293 573 700 or at medicalweb@caa.co.uk for confidential advice. For advice about a seafarer, you can contact the Maritime and Coastal Agency health and safety branch for advice at seafarers.h&s@mcga.gov.uk. If you are concerned that a train driver’s medical condition or treatment may make them unfit to drive a train, the advice from the Office of Rail and Road (ORR) is to make contact with the patient’s HR department in the first instance. The ORR can provide contact details for HR departments in Great Britain if you know the name of the employer.


5 You can contact the DVLA’s medical advisers on 01792 782 337 or at medadviser@dvla.gsi.gov.uk, and the DVA on 028 703 41369.
Confidentiality: disclosing information about serious communicable diseases

1 In our guidance *Confidentiality* we say:

7 Trust is an essential part of the doctor-patient relationship and confidentiality is central to this. Patients may avoid seeking medical help, or may under-report symptoms, if they think that their personal information will be disclosed by doctors without consent, or without the chance to have some control over the timing or amount of information shared.

22 You must disclose information if it is required by statute, or if you are ordered to do so by a judge or presiding officer of a court.

23 You should satisfy yourself that the disclosure is required by law and you should only disclose information that is relevant to the request. Wherever practicable, you should tell patients about such disclosures, unless that would undermine the purpose, for example by prejudicing the prevention or detection of serious crime.

67 You should ask for a patient’s consent to disclose information for the protection of others unless it is not safe or practicable to do so, or the information is required by law. You should consider any reasons given for refusal.

69 If it is not practicable to seek consent, and in exceptional cases where a patient has refused consent, disclosing personal information may be justified in the public interest if failure to do so may expose others to a risk of death or serious harm. The benefits to an individual or to society of the disclosure must outweigh both the public and the patient’s interest in keeping the information confidential.
If you consider that failure to disclose the information would leave individuals or society exposed to a risk so serious that it outweighs the patient’s and the public interest in maintaining confidentiality, you should disclose relevant information promptly to an appropriate person or authority. You should inform the patient before disclosing the information, if it is practicable and safe to do so, even if you intend to disclose without their consent.

About this guidance
2 Confidentiality is important to all patients and all patients are entitled to good standards of care, regardless of their status, what disease they might have, or how they acquired it. Those who have, or may have, a serious communicable disease might be particularly concerned about their privacy.2 This explanatory guidance sets out how the general principles in our guidance Confidentiality apply when doctors are accessing, using, or disclosing information about the infection status of patients who have serious communicable diseases.

Protecting information against improper disclosure
3 You should make sure that information you hold or control about a patient’s infection status is at all times effectively protected against improper disclosure. If you disclose information about a patient’s infection status, you must keep disclosures to the minimum necessary for the purpose.

Control and surveillance of serious communicable diseases
4 You must pass information about notifiable diseases to the relevant authorities for communicable disease control and surveillance. Different diseases are notifiable in different UK countries and the reporting arrangements differ. You should follow the arrangements where you work.3 You should disclose anonymised information if practicable and as long as it will serve the purpose.

Protecting patients from risks posed by your health or your colleagues’ health
5 Good medical practice4 says:
If you know or suspect that you have a serious condition that you could pass on to patients, or if your judgement or performance could be affected by a condition or its treatment, you must consult a suitably qualified colleague. You must follow their advice about any changes to your practice they consider necessary. You must not rely on your own assessment of the risk to patients.

You should be immunised against common serious communicable diseases (unless otherwise contraindicated).

You should follow our guidance *Raising and acting on concerns about patient safety* if you are concerned that a colleague who has a serious communicable disease is practising, or has practised, in a way that puts patients at risk of infection.

You should inform your colleague before passing the information on, as long as it is practicable and safe to do so.

### Disclosing information about patients who are diagnosed with a serious communicable disease to those providing direct care

Most patients understand and expect that relevant information must be shared within the direct care team to provide their care. If a patient objects to disclosure of personal information that you are convinced is essential to provide them with safe care, you should follow the guidance at paragraphs 35 and 36 of *Confidentiality*. If the patient does not have capacity to make the decision, you can disclose information if it is in their overall benefit, in line with the guidance at paragraphs 53 and 54 of *Confidentiality*.

If a patient who has been diagnosed with a serious communicable disease refuses to allow you to tell others providing their care about their infection status, and you believe that failing to disclose the information will put healthcare workers or other patients at risk of infection, you should explain to the patient the potential consequences of their decision and consider with the patient whether any compromise can be reached.
Like everyone else, healthcare workers are entitled to protection from risks of serious harm. But disclosure of information about a patient’s infection status without consent is unlikely to be justified if it would make no difference to the risk of transmission – for example if the risk is likely to be managed through the use of universal precautions that are already in place. If the patient continues to refuse to allow you to tell other members of the healthcare team about their infection status, you must abide by their wishes unless you consider that disclosing the information is necessary to protect healthcare workers or other patients from a risk of death or serious harm.

**Disclosing information in response to injuries to colleagues and others**

If a colleague, police officer or anyone else suffers a needlestick or similar injury involving a patient who has, or may have, a serious communicable disease, you should make sure that a risk assessment is made urgently by an appropriately qualified colleague. Post-exposure prophylaxis should be offered in accordance with that risk assessment, depending on the type of body fluid or substance involved and the route and severity of the exposure.

You should ask for the patient’s consent to disclose their infection status after other people have been exposed to a serious communicable disease. If the patient cannot be persuaded to consent to disclosure, or if it is not safe or practicable to ask for their consent, you may disclose information if it is justified in the public interest. This could be, for example, if the information is needed for decisions about the continued appropriateness of post-exposure prophylaxis.

**Informing people at risk of infection from serious communicable disease**

You should explain to patients who have serious communicable diseases how they can protect others from infection, including from sexually transmitted diseases. This includes the practical measures they can take to avoid transmission, and the importance of informing people with whom they have sexual contact about the risk of sexual transmission of serious communicable diseases.

You may disclose information to a person who has close contact with a patient who has a serious communicable disease if you have reason to think that:

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a. the person is at risk of infection that is likely to result in serious harm
b. the patient has not informed them and cannot be persuaded to do so.

14 If you believe that an adult who is at risk of infection lacks capacity to understand this information, and is at risk of serious harm, you must give relevant information promptly to an appropriate responsible person or authority, unless it is not of overall benefit to the patient to do so (see paragraphs 60 and 61 of Confidentiality).

15 You should tell the patient before you disclose the information if it is practicable and safe to do so. When you are tracing and notifying people, you should not disclose the identity of the patient, if practicable. You must be prepared to justify a decision to disclose personal information without consent.8

**Disclosing information when children and young people are at risk of a serious communicable disease**

16 Most patients with a serious communicable disease who are parents of, or care for, children will do all they can to protect the children from the risk of infection or the effects of the disease. You should make sure the patient understands the information and advice you give them, which you should tailor to their needs. You should do all you reasonably can to support them in caring for themselves and in protecting their children.

17 You should explain to a patient with a serious communicable disease the importance of testing any children who may already be infected, including children without symptoms and young people who might have been vertically infected with a blood-borne virus.

18 If you are concerned that a child is at risk of serious harm because their parents cannot be persuaded to protect them from the risk of infection, or because they refuse to allow the child to be tested, you should treat it as a safeguarding concern and follow the advice in our guidance *Protecting children and young people: the responsibilities of all doctors*.9
Recording serious communicable diseases on death certificates

19 If a serious communicable disease has contributed to the cause of death, you must record this on the patient’s death certificate.

Endnotes

1 We give examples of when it might not be practicable to seek consent in paragraph 19 of Confidentiality. You can find all of our guidance online at www.gmc-uk.org/guidance.

2 In this guidance, the term ‘serious communicable disease’ applies to any disease that can be transmitted from human to human and that can result in death or serious illness. It particularly applies to, but is not limited to, HIV, tuberculosis, and hepatitis B and C.

3 You can get advice from the Health Protection Agency in England, Public Health Wales, Communicable Disease Surveillance Centre in Northern Ireland and Health Protection Scotland.

4 Good medical practice (General Medical Council, 2013). You can find all of our guidance online at www.gmc-uk.org/guidance.


6 Universal precautions, otherwise known as standard infection control precautions, are the basic infection prevention and control measures necessary to reduce the risk of transmitting infectious agents. Guidance on infection control is provided by Health Protection Scotland, NHS Wales, DHSSPS Northern Ireland and the Department of Health in England.


8 The NHS (Venereal Diseases) Regulations 1974, The NHS Trusts (Venereal Diseases) Directions 1991 and The NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000 state that various NHS bodies in England and Wales must ‘take all necessary steps to secure that any information capable of identifying an individual… with respect to persons examined or treated for any sexually transmitted disease shall not be disclosed except – (a) for the purpose of communicating that information to a medical practitioner, or to a person employed under the direction of a medical practitioner in connection with the treatment of persons suffering from such disease or the prevention of the spread thereof, and (b) for the purpose of such treatment and prevention’. There are different interpretations of the regulations and directions, and concerns about their compatibility with the European Convention on Human Rights. In particular, there have been concerns that a strict interpretation would prevent the disclosure of relevant information, except to other doctors or those working under their supervision, even with the patient’s consent or to known sexual contacts in the public interest. Our view is that the regulations and directions do not preclude disclosure if it would otherwise be lawful at common law, for example with the patient’s consent or in the public interest without consent.

9 See also our case study about a parent who refuses to allow her daughter to be tested for HIV, available at www.gmc-uk.org/guidance/ethical_guidance/13561.asp.
Confidentiality: disclosing information for employment, insurance and similar purposes

1 In our guidance *Confidentiality* we say:

120 Third parties, such as a patient’s insurer or employer, or a government department, or an agency assessing a claimant’s entitlement to benefits, may ask you for personal information about a patient, either following an examination or from existing records. In these cases, you should:

a be satisfied that the patient has sufficient information about the scope, purpose and likely consequences of the examination and disclosure, and the fact that relevant information cannot be concealed or withheld

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. You may accept an assurance from an officer of a government department or agency, or a registered health professional acting on their behalf, that the patient or a person properly authorised to act on their behalf has consented

c only disclose factual information you can substantiate, presented in an unbiased manner, which is relevant to the request. You should not usually disclose the whole record, although it may be relevant to some benefits paid by government departments and to other assessments of a patient’s entitlement to pensions or other health-related benefits

d offer to show your patient, or give them a copy of, any report you write about them for employment or insurance purposes before it is sent, unless:

i they have already indicated they do not wish to see it

ii disclosure would be likely to cause serious harm to the patient or anyone else
iii disclosure would be likely to reveal information about another person who does not consent.1

About this guidance
2 One of the core duties of a doctor is to make the care of your patient your first concern.2 There are, however, many circumstances in which you might be asked to disclose information from existing records or after examining a patient, and in which you face dual obligations. By this we mean that you have obligations both to the patient and to the person or organisation that has requested the information.

3 This explanatory guidance sets out how the general principles in our guidance Confidentiality apply when patient information is being disclosed in these circumstances. The guidance applies to disclosure of information obtained directly from a patient, or from a patient’s medical record, or from another health professional. It does not apply if opinions are based solely on information provided by the person or body that is commissioning the opinion.

When do dual obligations arise?
4 Usually, dual obligations arise when a doctor works for, is contracted by, or otherwise provides services to:

- a patient’s employer (as an occupational health doctor)
- an insurance company
- an agency assessing a claimant’s entitlement to benefits
- the police (as a police surgeon)
- the armed forces
- the prison service
- a sports team or association.3

5 Alternatively, a person or organisation you have previously had no direct relationship with, such as your patient’s employer or insurance company, might ask you to provide
a medical report or information about a patient. You might be offered payment for your own or your staff’s time and effort, giving rise to an obligation in addition to the one you have to your patient.\(^4\)

**How much information should you disclose?**

6 You should only disclose information that is relevant to the request, which means you should not usually disclose a patient’s whole record.\(^5\) There are two exceptions to this general rule.

- **Benefit claims:** the patient’s whole record may be relevant to some benefits paid by government departments or agencies.\(^6\)

- **Legal processes:** a solicitor may need to see their client’s whole record to assess which parts are relevant, for example to personal injury claims. If the claim goes ahead, the person against whom the claim is made may ask for copies of important documents, which could include records containing the patient’s medical history. Under court rules in England and Wales, they can see the patient’s whole record and the solicitor should explain this to the patient. In Northern Ireland and Scotland, you should disclose your patient’s record in accordance with their wishes or as ordered by a court.\(^7\)

**Writing reports**

7 When writing a report\(^8\) you must:

- **a** make sure it is not false or misleading – you must take reasonable steps to check the information in the report is correct, and you must not deliberately leave out relevant information

- **b** restrict the report to areas in which you have direct experience or relevant knowledge

- **c** make sure any opinion you include is balanced, and be able to state the facts or assumptions on which it is based.

**Disclosing a report about a patient**

8 You do not need to ask for separate consent to release a report following an examination as long as you are satisfied that the patient has given informed consent
both for the examination and for the release of any subsequent reports (see paragraph 120 of *Confidentiality*, which is reproduced at the top of this statement).

9 You should, however, usually offer to show your patient or give them a copy of any report you write about them for employment or insurance purposes before it is sent.9

10 If a patient asks you to amend a report, you should correct any errors of fact and any opinion that is based on errors of fact. You should not remove information, opinion or advice if you believe the report would be false or misleading as a result.

11 If a patient withdraws consent for the report to be disclosed, it may be appropriate for you to tell the patient that their decision may lead to adverse consequences for them. For example, the absence of occupational health information could disadvantage the patient in negotiations with their employer. You must, however, respect the patient’s wishes unless the disclosure is required by law (see paragraph 14) or can be justified in the public interest (see paragraph 15).

12 If a patient withdraws consent for a report to be disclosed, or fails to attend an appointment, you can let the report commissioner know but you should not disclose any further information.

13 When you are satisfied that a report should be disclosed, you should complete and send the report without unreasonable delay.

**Disclosures required by law**

14 You must disclose information if it is required by law or by the courts. If a disclosure is required by law, you should follow the guidance at paragraphs 92–99 of *Confidentiality*. If you are not sure whether a disclosure is required by law, you should ask the person or body requesting the information to identify the legal basis, or seek independent legal advice.
Disclosures in the public interest

15 Disclosing personal information about a patient without consent may be justified in the public interest if failure to do so may expose others to a risk of death or serious harm. This could arise, for example, if a patient may pose a serious risk to others through being unfit for work. If you think that a disclosure may be justified in the public interest you should follow the guidance at paragraphs 68–75 of Confidentiality.

Endnotes

1 You can find Confidentiality, and the rest of our guidance, online at www.gmc-uk.org/guidance.

2 The term ‘patient’ in this guidance refers to employees, clients, claimants, athletes and anyone else whose personal information you hold or have access to, whether or not you care for them in a traditional therapeutic relationship.

3 Doctors might provide their services to professional sports clubs (where the dual obligation is to both the patient and the club, which is very similar to the dual obligation of an occupational health doctor) or to associations (where the dual obligation is both to the patient and to a governing body or team of selectors).

4 This guidance is not intended for doctors who act as expert witnesses. We give specific guidance in Acting as a witness in legal proceedings, which you can find at www.gmc-uk.org/guidance.

5 Disclosure of the whole record may breach the principles of the Data Protection Act 1998, as the full record may contain information that is excessive and not relevant for the purpose. The Information Commissioner’s Office (ICO) has advised that it is not appropriate for insurance companies to obtain medical records using patients’ subject access requests. The Access to Medical Reports Act 1988 gives insurance companies a clear and established legal route to access medical information, while safeguarding patients’ rights. You can find the ICO statement at https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2015/07/insurers-using-subject-access-requests-to-see-medical-information/.


7 The Law Society and British Medical Association jointly publish model consent forms authorising the release of health records to solicitors under the Data Protection Act 1998. The forms include notes for clients, solicitors and medical records controllers. You can find them at www.bma.org.uk/support-at-work/ethics/confidentiality-and-health-records.

8 See Good medical practice, paragraphs 71–74, which you can find at www.gmc-uk.org/guidance.

9 Under the Access to Medical Reports Act 1988, patients are entitled to see a report that has been written about them for employment or insurance purposes by a doctor who is or has been responsible for the clinical care of the individual before it is sent, unless exceptions apply. Patients have the right to ask the doctor to amend any part of the report that the patient considers to be incorrect or misleading, and to attach their
disagreement to the report, or to withdraw their consent for the release of the information. These provisions do not apply to reports for benefits purposes. If the patient has no legal right to see the report before it is sent, you should follow the guidance in paragraph 120(d) of Confidentiality, which is reproduced at the start of this explanatory guidance. If any of the exceptions set out in paragraph 120(d) apply, you should still disclose as much of the report as you can.
Confidentiality: disclosing information for education and training purposes

In our guidance *Confidentiality* we say:

82 Many important uses of patient information contribute to the overall delivery of health and social care. Examples include health services management, research, epidemiology, public health surveillance, and education and training. Without information about patients the health and social care system would be unable to plan, develop, innovate, conduct research or be publicly accountable for the services it provides.

84 Anonymised information will usually be sufficient for purposes other than the direct care of the patient and you must use it in preference to personal information wherever possible. If you disclose identifiable information for purposes other than a patient’s direct care or local clinical audit you must be satisfied that there is a legal basis for breaching confidentiality.

85 You may disclose personal information without breaching duties of confidentiality when any of the following circumstances apply.

   a. The disclosure is required by law (see paragraphs 92–99).
   b. The patient has given explicit consent (see paragraph 100).
   c. The disclosure is approved through a statutory process which sets aside the common law duty of confidentiality (see paragraphs 108–110).
   d. The disclosure can, exceptionally, be justified in the public interest (see paragraphs 111–117).

You must also be satisfied that the other relevant requirements for disclosing information are met (see paragraph 15).
About this guidance

2 The use of information about patients is essential to the education and training of medical students, doctors in training and other healthcare students and trainees. This explanatory guidance sets out how the general principles in our guidance Confidentiality apply in the particular context of education and training.

General principles

3 For most education and training uses, anonymised information will be sufficient and must be used whenever practicable. If it is necessary to use identifiable information about a patient, or it is not practicable to anonymise information, you should usually ask for the patient’s explicit consent before disclosing it to anyone who is not part of the team that is providing or supporting the patient’s direct care. You should make sure that the patient is under no pressure to consent. In particular, you should avoid any impression that their care depends on giving consent.²

Teaching and training of medical students, doctors in training and other healthcare students and trainees

4 Most patients understand and accept that the education and training of medical students, doctors in training and other healthcare students and trainees relies on them having access to information about patients. If doctors in training or medical or healthcare students are part of the team providing or supporting a patient’s direct care,³ they can have access to the patient’s personal information, just as other team members do, unless the patient objects.⁴

5 If the doctor or student is not providing or supporting the patient’s care, anonymised information should be used for education and training purposes whenever practicable. This may not be achievable, for example, on ward rounds, but it will then usually be possible to seek the patient’s explicit consent to disclosure.

6 In some cases it might be necessary to disclose personal information, or not practicable to anonymise it, or to ask for a patient’s consent. In such cases you may disclose relevant personal information to medical students, doctors in training and other healthcare students and trainees, as long as you are satisfied that information has been made readily available to the patient about the disclosure and of their right
to object, and they have not objected. You must also be satisfied that they understand that the information is given in confidence, which they must respect.

**Patients who lack capacity**

7  You should not disclose personal information for education and training purposes about patients who lack capacity if you can use information about other patients instead.

8  If you wish to disclose personal information about a patient who currently lacks capacity (for example, because they are acutely unwell), but who is likely to regain capacity, you should wait and ask for their consent later if you can.

9  If you are asked, or want, to disclose information about a patient who lacks capacity, you should seek the views of anyone the patient asks you to consult, or who has legal authority to make decisions on their behalf, or who has a close personal relationship with the patient. They may be able to give you an indication of the patient’s previously expressed preferences, views and beliefs.

10 In the absence of any indication about the preferences of a patient who lacks capacity, you should not publish information from which they can be identified. In exceptional cases, however, you may disclose relevant personal information to medical students, doctors in training and other healthcare students and trainees if it is necessary for their education and training. You must be satisfied there is no reasonably practicable alternative to using personal information, and you should have no reason to believe that it is contrary to the interests of the patient to do so.

**Disclosing information to secondary school and college students**

11 Doctors are sometimes asked to provide work experience for secondary school or further education college students, which may include allowing them to be present during consultations with patients.

12 You should ask for the patient’s explicit consent to a student observing their care. You should also satisfy yourself that the student’s presence does not adversely affect the patient’s care, for example by inhibiting frank discussion.

www.gmc-uk.org
13 You should satisfy yourself that the student understands the importance of respecting confidentiality and that their school or college takes seriously its responsibilities for its students’ conduct.  

Training records and case studies
14 You must anonymise patient information in training records and case studies as far as it is possible to do so. The anonymisation code of practice published by the Information Commissioner’s Office considers data to be anonymised if it does not itself identify any individual, and if it is unlikely to allow any individual to be identified through its combination with other data. Simply removing the patient’s name, age, address or other personal identifiers is unlikely to be enough to anonymise information to this standard.

15 If it is difficult to anonymise information about patients while retaining enough detail to make a training record useful, or if it is necessary to include identifiers (such as the patient’s hospital number) to allow the record to be audited, you should ask for the patient’s consent to use their information if you can. If is not practicable to seek the patient’s consent, you may use potentially identifiable information in a training record as long as you are satisfied that the record will be kept securely and will be managed in accordance with other data protection requirements. You must still remove as many identifiers as you can.

16 If the information is likely to be more widely accessible (for example, in discussion at a seminar or conference, or published in a journal), and you consider that the patient could be identified, you should usually use the information only when you have the patient’s explicit consent.

17 When asking for the patient’s consent, you must give the patient enough information about the nature and purpose of the disclosure to enable them to make an informed decision. This should include a description of the information to be disclosed and an indication of who will have access to it and how it will be used.

18 You may disclose information only for the purposes for which the patient has given consent, and you must remove as many identifiers as you can. You must respect a patient’s refusal to consent to the publication of their identifiable information.
If for any reason you cannot get a patient’s consent – for example, because the information you want to disclose is so old that efforts to trace the patient have been or are likely to be unsuccessful – you will need to consider whether disclosing potentially identifiable information can be justified in the public interest. You should seek advice from a Caldicott or data guardian or a legal adviser, who is not directly connected with the use for which the disclosure is being considered, before disclosing personal information without consent.

Endnotes

1 All paragraph numbers in this section refer to our guidance Confidentiality. You can find all of our guidance online at www.gmc-uk.org/guidance.

2 See our guidance Consent: patients and doctors making decisions together, which states that you must give patients the information they want or need about the extent to which students may be involved in their care, and of their right to refuse to take part in teaching.

3 In this guidance, direct care refers to activities that directly contribute to the diagnosis, care and treatment of an individual. The direct care team is made up of those health and social care professionals who provide direct care to the patient and others, such as administrative staff, who directly support that care.

4 See paragraphs 33–36 of Confidentiality for advice on implied consent.

5 Welfare attorneys, court-appointed guardians and court-appointed deputies have legal authority to make some decisions on a patient's behalf. For disclosure in the public interest, you will be seeking their views about the patient’s preferences, rather than their consent to disclose.


8 Other potential identifiers include the patient's initials, postcode, NHS or CHC number, local identifiers (such as hospital numbers), national insurance number, and key dates (such as birthdate, date of diagnosis or date of death).

9 See paragraphs 111–117 of Confidentiality for guidance on assessing whether a disclosure would be justified in the public interest.
Responding to criticism in the media

1 In our guidance *Confidentiality* we say:

7 Trust is an essential part of the doctor-patient relationship and confidentiality is central to this. Patients may avoid seeking medical help, or may under-report symptoms, if they think that their personal information will be disclosed by doctors without consent, or without the chance to have some control over the timing or amount of information shared.

About this guidance

2 Doctors are sometimes criticised in the print or broadcast media or on social media by their patients or by someone who is close to, or who represents, a patient. The criticism can include inaccurate or misleading details of the doctor’s diagnosis, treatment or behaviour. Although this can be frustrating or distressing, it does not relieve you of your duty to respect your patient’s confidentiality. This explanatory guidance sets out how the general principles in our guidance *Confidentiality* apply when doctors are considering how to respond to criticism in the media.

Responding to criticism

3 Disclosures of patient information without consent can undermine the public’s trust in the profession as well as your patient’s trust in you. Disputes between patients and doctors conducted in public can also prolong or intensify conflict and may undermine
public confidence in the profession, even if they do not involve the disclosure of personal information without consent.

4 You must not put information you have learned in confidence about a patient in the public domain without that patient’s explicit consent. You should usually limit your public response to an explanation of your legal and professional duty of confidentiality.

5 However, from time to time, media reports or social media discussions might cause patients to be concerned about your practice, or that of a health service you are associated with. In such cases it may be appropriate to give general information about your normal practice. You must be careful not to reveal personal information about a patient, or to give an account of their care, without their consent. If you deny allegations that appear in public media, you must be careful not to reveal, directly or by omission or inference, any more personal information about the patient than a simple denial demands.

6 You should seek advice from your professional or defence body, or from a solicitor, on how to respond to criticism in the media and, if appropriate, any legal redress available to you.

Endnotes

1 See also our guidance Doctors’ use of social media. You can find all of our guidance online at www.gmcuk.org/guidance.

2 In this guidance, ‘patient’ refers to both current and former patients.
Confidentiality consultation activities

Background

1 The consultation on the revised Confidentiality guidance ran for a twelve-week period from 25 November 2015 to 19 February 2016. This paper provides a summary of the various consultation activities during that time.

2 The main aims of the consultation were to test that the draft guidance is clear, relevant, achievable, consistent with the law, and that it reflects common ground between patients/the public and the medical profession about what good practice looks like.

3 For the consultation to be meaningful and credible, we needed to provide sufficient and appropriate opportunities for key interest groups to inform decisions about the content. The Task and Finish Group identified the absence of the ‘patient voice’ as a significant gap in the evidence gathered during the initial stages of the review, so it was particularly important to hear from patients and those representing them.

4 We employed three methods to gather views on the draft and the issues raised in the guidance:

- consultation questionnaires
- research commissioned from Ipsos MORI exploring patient and public attitudes towards particular issues in the draft guidance
- direct engagement with doctors, patients and key policy stakeholders.

Questionnaires

5 We produced four questionnaires, which could be completed online, or submitted via email or in hardcopy.
The main questionnaire (36 questions) which assumed that the respondent had read the draft core guidance.

Two short questionnaires aimed respectively at doctors and other healthcare professionals (11 questions) and patients and the public (10 questions) which addressed some of the issues covered in the guidance but did not require respondents to have read the draft guidance.

A questionnaire covering the seven explanatory guidance statements and the confidentiality section of 0-18 years: guidance for all doctors.

In total we received 193 responses across the four questionnaires.

49 responses came from organisations, including 12 from postgraduate medical institutions, six from bodies representing doctors, six from NHS/Social care organisations, five from bodies representing patients or the public and five from Government departments. A full list of organisational respondents is attached at Appendix A.

Responses from individuals included 65 from doctors, 30 from members of the public, and 15 from respondents who identified themselves as ‘other healthcare professionals’.

Engagement activities and policy meetings

During the consultation period the Regional Liaison Service, devolved office staff and the policy team engaged face to face with just over 1,000 individuals.

Engagement activities were held in all four UK countries and employed a mixture of formats - quick votes on specific questions or short case study discussions as part more general events, and meetings dedicated entirely to discussion of confidentiality issues and the consultation.

Delegates were primarily:

- doctors – including FY1/2s, doctors in training, SAS doctors, consultants, GPs, International Medical Graduates, LGBT doctors
- patients – including Healthwatch groups, BME carers, older people and their advocates, transgender people.

A full list of the engagement activities is attached at Appendix B.

The policy team also held or attended 13 meetings with internal and external stakeholders who have a particular interest in aspects of the guidance. A list is attached at Appendix C.
Ipsos MORI research

12 We commissioned Ipsos MORI to undertake research with groups of patients and members of the public that we had identified as potentially having particular concerns around confidentiality but who might be less likely to take part in a formal written consultation, and who we would find it difficult to identify or recruit to our own engagement events.

13 During January and February 2016, Ipsos MORI spoke to 86 people, in a series of discussion/focus groups and individual in-depth interviews, about their views on patient confidentiality. Fictional case studies were used to stimulate discussion on topics thought to be particularly relevant to particular groups because of reasons related to cultural and/or religious background, gender and/or age or enhanced privacy concerns.

14 Participants included older people resident in care homes, members of the gypsy and traveller community, people who have experienced domestic violence and asylum seekers and refugees. Groups and interviews were carried out across the UK and in rural and city locations. A list is attached at Appendix D.

15 The research found very high levels of agreement with the principles outlined in the draft guidance. The report is available on the GMC website at: http://www.gmc-uk.org/about/research/29111.asp.

Analysis of consultation material and independent audit

16 The consultation responses and outputs from engagement activities were analysed in line with the GMC’s general approach to consultation analysis, a process which has been found by independent audit to be structured, systematic and likely to lead to a high degree of consistency of interpretation.

17 A sample audit of this analysis found some inconsistencies in the ways statistics were reported in the analysis papers, although this did not affect the validity of any conclusions that were drawn. There was also an oversight in one piece of analysis due to a mislabelling of an analysis spreadsheet, which led to some responses not being analysed. This has been rectified. The overall conclusion of the audit was, however, that ‘the analysis of the consultation is an accurate reflection of respondents’ views. Likewise these views are well documented in the papers produced for the Task and Finish Groups.’
## Appendix A - Organisation respondents

<table>
<thead>
<tr>
<th>Country</th>
<th>Organisation Name</th>
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</thead>
<tbody>
<tr>
<td>England</td>
<td>Association of Directors of Adult Social Services (ADASS)</td>
</tr>
<tr>
<td>UK wide</td>
<td>BLM</td>
</tr>
<tr>
<td>UK wide</td>
<td>British HIV Association</td>
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<tr>
<td>UK wide</td>
<td>British Medical Association</td>
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<td>UK wide</td>
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<td>Northern Ireland</td>
<td>Disability Action</td>
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<tr>
<td>UK wide</td>
<td>Faculty of Intensive Care Medicine</td>
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<tr>
<td>UK wide</td>
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<td>England</td>
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<td>UK wide</td>
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## Country | Organisation Name

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<td>Medical and Dental Defence Union of Scotland</td>
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## Appendix B - Consultation engagements

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<th>Participants</th>
<th>No. of attendees</th>
<th>Engagement type</th>
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<td></td>
<td></td>
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<td>RLS</td>
<td>Patients</td>
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<td>Devolved office LA</td>
<td>Patient advocates – older patients</td>
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<td>Policy team</td>
<td>Patients</td>
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<td>MECOPP - Chinese carers, Edinburgh</td>
<td>Policy team and devolved office</td>
<td>Patients - BME</td>
<td>10</td>
<td>Full session</td>
</tr>
<tr>
<td>MECOPP - South Asian carers</td>
<td>Policy team and devolved office</td>
<td>Patients - BME</td>
<td>11</td>
<td>Full session</td>
</tr>
<tr>
<td>Age Cymru, Cardiff</td>
<td>Policy team and devolved office</td>
<td>Patients – older adults</td>
<td>?</td>
<td>Full session</td>
</tr>
<tr>
<td>Healthwatch Peterborough</td>
<td>RLS</td>
<td>Patients</td>
<td>10</td>
<td>Full session</td>
</tr>
<tr>
<td>City Healthwatch</td>
<td>RLS</td>
<td>Patients</td>
<td>14</td>
<td>Mini session</td>
</tr>
<tr>
<td>Healthwatch Torbay</td>
<td>RLS</td>
<td>Patients</td>
<td>25</td>
<td>Full session</td>
</tr>
<tr>
<td>Manchester Healthwatch, Freedom Group and youth trans groups, Manchester medical students</td>
<td>RLS</td>
<td>Patients: 13 trans, 2 LGB and 14 Medical students</td>
<td>28</td>
<td>Full session</td>
</tr>
<tr>
<td>Health Council Scotland</td>
<td>Policy team and devolved office</td>
<td>Patients</td>
<td>5</td>
<td>Full session</td>
</tr>
<tr>
<td><strong>Doctors, other health professionals, students</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University Hospitals of Morecambe Bay</td>
<td>RLS</td>
<td>Foundation doctors (FY1)</td>
<td>30</td>
<td>Mini session</td>
</tr>
<tr>
<td>Northumbria Healthcare NHS Foundation Trust</td>
<td>RLS</td>
<td>Foundation doctors (FY2)</td>
<td>10</td>
<td>Full session</td>
</tr>
<tr>
<td>Hampshire</td>
<td>RLS</td>
<td>Foundation doctors (FY1 &amp; FY2)</td>
<td>26</td>
<td>Voting only</td>
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### Event

<table>
<thead>
<tr>
<th>Event</th>
<th>Facilitator</th>
<th>Participants</th>
<th>No. of attendees</th>
<th>Engagement type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kingston Hospital Postgraduate Centre</td>
<td>RLS</td>
<td>Foundation doctors (FY2)</td>
<td>17</td>
<td>Voting only</td>
</tr>
<tr>
<td>Royal Gwent Hospital, Newport</td>
<td>Devolved office LA</td>
<td>Foundation doctors (FY2)</td>
<td>19</td>
<td>Voting only</td>
</tr>
<tr>
<td>Homerton University hospital</td>
<td>RLS</td>
<td>Foundation doctors (FY2)</td>
<td>20</td>
<td>Mini session</td>
</tr>
<tr>
<td>Pennine Acute NHS Foundation Trust</td>
<td>RLS</td>
<td>Foundation doctors (FY1)</td>
<td>35</td>
<td>Mini session</td>
</tr>
<tr>
<td>Plymouth Hospital</td>
<td>RLS</td>
<td>Foundation doctors (FY1)</td>
<td>32</td>
<td>Mini session</td>
</tr>
<tr>
<td>Lewisham and Greenwich NHS Trust University Hospital</td>
<td>RLS</td>
<td>Foundation doctors (FY1)</td>
<td>9</td>
<td>Mini session</td>
</tr>
<tr>
<td>GP Vocational Training Scheme session</td>
<td>RLS</td>
<td>Doctors in Training (GPs)</td>
<td>25</td>
<td>Voting only</td>
</tr>
<tr>
<td>GP Vocational Training Scheme session</td>
<td>RLS</td>
<td>Doctors in Training (GPs)</td>
<td>28</td>
<td>Voting only</td>
</tr>
<tr>
<td>Chelsea and Westminster Post Graduate Centre</td>
<td>RLS</td>
<td>Doctors in Training (core medical)</td>
<td>7</td>
<td>Mini session</td>
</tr>
<tr>
<td>Leicestershire General Hospital</td>
<td>RLS</td>
<td>GP Trainees</td>
<td>30</td>
<td>Mini session</td>
</tr>
<tr>
<td>West Lakes Trainee Event (Cumbria)</td>
<td>RLS</td>
<td>Doctors in Training (GPs)</td>
<td>7</td>
<td>Mini session</td>
</tr>
<tr>
<td>Northern Ireland Medical and Dental Training Agency</td>
<td>Devolved office LA</td>
<td>Doctors in Training (core medical)</td>
<td>13</td>
<td>Mini session</td>
</tr>
<tr>
<td>Buckingham Medical School</td>
<td>RLS</td>
<td>Medical Students</td>
<td>77</td>
<td>Voting only</td>
</tr>
<tr>
<td>Russells Hall Hospital, Dudley</td>
<td>RLS</td>
<td>Acute doctors</td>
<td>10</td>
<td>Mini session</td>
</tr>
<tr>
<td>Russells Hall Hospital Dudley</td>
<td>RLS</td>
<td>Consultants</td>
<td>24</td>
<td>Mini session</td>
</tr>
<tr>
<td>SARCs (Sexual Assault Referral Centres)</td>
<td>RLS</td>
<td>Community doctors, nurses and AHPs</td>
<td>60</td>
<td>Full session</td>
</tr>
<tr>
<td>BHIVA (British HIV Association) and BASHH (British Association for Sexual Health and HIV)</td>
<td>RLS</td>
<td>Secondary Care Doctors, nurses and AHPs (Sexual Health)</td>
<td>30</td>
<td>Full session</td>
</tr>
<tr>
<td>Hinchingbrooke Hospital</td>
<td>RLS</td>
<td>Acute Trust Doctors</td>
<td>13</td>
<td>Voting only</td>
</tr>
<tr>
<td>Welcome to UK Practice, London</td>
<td>RLS</td>
<td>Doctors</td>
<td>19</td>
<td>Voting only</td>
</tr>
<tr>
<td>Event</td>
<td>Facilitator</td>
<td>Participants</td>
<td>No. of attendees</td>
<td>Engagement type</td>
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<tr>
<td>------------------------------------</td>
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</tr>
<tr>
<td>Welcome to UK Practice, London</td>
<td>RLS</td>
<td>Doctors</td>
<td>25</td>
<td>Voting only</td>
</tr>
<tr>
<td>GLADD Annual Conference</td>
<td>RLS</td>
<td>LGBT Doctors &amp; Medical Students</td>
<td>70</td>
<td>Mini session</td>
</tr>
<tr>
<td>Frimley Health NHS Foundation Trust</td>
<td>RLS</td>
<td>SAS doctors</td>
<td>16</td>
<td>Mini session</td>
</tr>
<tr>
<td>Barking, Havering and Redbridge Trust</td>
<td>RLS</td>
<td>SAS doctors</td>
<td>14</td>
<td>Voting only</td>
</tr>
<tr>
<td>Haringey and Enfield</td>
<td>RLS</td>
<td>GPs</td>
<td>14</td>
<td>Voting only</td>
</tr>
<tr>
<td>Camden &amp; Islington</td>
<td>RLS</td>
<td>Psychiatrists</td>
<td>25</td>
<td>Voting only</td>
</tr>
<tr>
<td>UK Professionalism Teachers</td>
<td>RLS</td>
<td>Medical Educationalists</td>
<td>24</td>
<td>Mini session</td>
</tr>
<tr>
<td>St George's University Hospitals NHS Foundation Trust</td>
<td>RLS</td>
<td>Psychiatrists</td>
<td>31</td>
<td>Voting only</td>
</tr>
<tr>
<td>Taunton and Somerset NHS FT</td>
<td>RLS</td>
<td>Acute Trust doctors</td>
<td>2</td>
<td>Voting only</td>
</tr>
<tr>
<td>All Gwent Postgraduate Programme, St. Cadoc's Hospital, Caerleon, Newport</td>
<td>Devolved office LA</td>
<td>Mix of doctors and medical students</td>
<td>35</td>
<td>Full session</td>
</tr>
<tr>
<td>Lothian Ethics Group</td>
<td>Devolved office LA</td>
<td>Doctors and educators</td>
<td>9</td>
<td>Full session</td>
</tr>
<tr>
<td>Morriston Hospital (ABMU Health Board) Grand Round</td>
<td>Devolved office LA</td>
<td>Doctors</td>
<td>40</td>
<td>Full session</td>
</tr>
</tbody>
</table>

**Key**

Voting only – up to 4 questions, using ‘Turning point’ voting software

Mini session – voting plus one or more scenarios, as part of wider session

Full session – dedicated confidentiality consultation event
# Appendix C - Policy meetings

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
</tr>
</thead>
<tbody>
<tr>
<td>28/01/16</td>
<td>National Data Guardian Panel</td>
</tr>
<tr>
<td>04/12/16</td>
<td>GMC BME Doctors forum</td>
</tr>
<tr>
<td>09/02/16</td>
<td>Policy round table, Belfast (Privacy Advisory Committee, Royal College</td>
</tr>
<tr>
<td></td>
<td>of Surgeons, ECR Project Team, HSCB, QUB)</td>
</tr>
<tr>
<td>21/01/16</td>
<td>Policy round table, Edinburgh (BMA, MPS, Scottish Government, Care In</td>
</tr>
<tr>
<td></td>
<td>spectorate, Health Informatics Centre, Privacy Panel, National Services</td>
</tr>
<tr>
<td></td>
<td>Scotland)</td>
</tr>
<tr>
<td>02/02/16</td>
<td>Policy round table, Cardiff (Mencap Cymru, NHS Wales Informatics Serv</td>
</tr>
<tr>
<td></td>
<td>ice, Welsh Government Information Standards and Governance, Dean of Me</td>
</tr>
<tr>
<td></td>
<td>dical Education Swansea University, Director C21 Programme Cardiff Unive</td>
</tr>
<tr>
<td></td>
<td>rsity)</td>
</tr>
<tr>
<td>13/01/16</td>
<td>UK Council of Caldicott Guardians</td>
</tr>
<tr>
<td>09/02/16</td>
<td>NI Electronic Care Record Project team</td>
</tr>
<tr>
<td>10/02/16</td>
<td>Department of Work and Pensions</td>
</tr>
<tr>
<td>04/02/16</td>
<td>Faculty of Occupational Health</td>
</tr>
<tr>
<td>28/1/16</td>
<td>Chair of UK Council of Caldicott Guardians</td>
</tr>
<tr>
<td>12/01/16</td>
<td>Professor Martin Severs, HSCIC</td>
</tr>
<tr>
<td>13/1/16</td>
<td>GMC Education and Training Board</td>
</tr>
<tr>
<td>24/6/16</td>
<td>Policy roundtable on sharing information without consent (BMA, Metrop</td>
</tr>
<tr>
<td></td>
<td>olitan Police, Tender, Law Society of Scotland, SafeLives, Associatio</td>
</tr>
<tr>
<td></td>
<td>n of Directors of Adult Social Services, City and Hackney CCG, Safer</td>
</tr>
<tr>
<td></td>
<td>Wales, Independent Chair, a London Borough Safeguarding Adults Board)</td>
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## Appendix D - Participants in Ipsos MORI research

<table>
<thead>
<tr>
<th>Group of interest</th>
<th>Location</th>
<th>Research method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older people living in care homes</td>
<td>Leeds</td>
<td>Discussion group (6 people)</td>
</tr>
<tr>
<td>Carers</td>
<td>Rural Wales</td>
<td>Discussion group (8 people)</td>
</tr>
<tr>
<td>Young people (1st group)</td>
<td>Newcastle</td>
<td>Discussion group (8 people)</td>
</tr>
<tr>
<td>Young people (2nd group)</td>
<td>Belfast</td>
<td>Discussion group (8 people)</td>
</tr>
<tr>
<td>People from black and minority ethnic groups</td>
<td>Manchester</td>
<td>Discussion group (8 people)</td>
</tr>
<tr>
<td>Gypsies and Travellers</td>
<td>South East England – Rural</td>
<td>2 discussion groups (6 people in each)</td>
</tr>
<tr>
<td>Asylum seekers and refugees</td>
<td>London</td>
<td>Depth interviews (6 people)</td>
</tr>
<tr>
<td>People with mental health problems and/or their carers</td>
<td>South East England</td>
<td>Depth interviews (6 people)</td>
</tr>
<tr>
<td>People who have experienced detention by the state</td>
<td>Scotland</td>
<td>Depth interviews (6 people)</td>
</tr>
<tr>
<td>People who have experienced domestic violence</td>
<td>London</td>
<td>Depth interviews (6 people)</td>
</tr>
<tr>
<td>People with rare medical conditions</td>
<td>England, Scotland, Northern Ireland &amp; Wales</td>
<td>Online group (6 people)</td>
</tr>
<tr>
<td>Transgender people</td>
<td>England, Scotland, Northern Ireland &amp; Wales</td>
<td>Online group (6 people)</td>
</tr>
</tbody>
</table>
6 - Confidentiality guidance

Confidentiality consultation outcomes

1 This paper provides a summary of the consultation outcomes for the core guidance, and the seven explanatory statements that accompany it.

Core guidance

Structure

2 A strong message in pre-consultation feedback was that the structure of the guidance should more obviously reflect the ways in which patient information is used in practice. We therefore structured the consultation draft around three purposes for which patient information would be used, accessed or disclosed. These were for direct care, indirect care, and non-care purposes.

3 While a high percentage of respondents approved of this structure (86%) some significant concerns were expressed in the comments. The main concerns raised were as follows.

- **Repetition.** The revised structure introduced significant repetition, which some respondents thought made the guidance more complex and more difficult to navigate than it needs to be.

- **Artificial boundaries.** Several respondents questioned the value of distinguishing between non-care and indirect care purposes (given that the underlying principles are the same) and some argued that the distinction is artificial, and is not supported by law. It was also clear that many respondents were trying to work out which parts of the guidance apply to their work – for example some occupational health doctors clearly thought they only needed to abide by the ‘indirect care’ section, whereas others thought they needed to abide by the ‘non-care’ section. The risk inherent in this is that doctors may interpret parts of the guidance as not applying to their work, when all of the guidance is potentially relevant, depending on the purpose of a disclosure.

- **Terminology and conceptual coherence.** There was considerable uncertainty about what was captured within the concept of ‘indirect care’ and whether it is a valid and coherent category of activity. Other respondents objected to the terminology of
'non-care', as they felt the implication was that these purposes were less important than care-related purposes.

4 These comments suggest that, while trying to make the guidance helpful in practice, we inadvertently created artificial distinctions between indirect care and non-care purposes that could cause significant difficulties for doctors applying the guidance, and for the GMC in carrying out its fitness to practise functions.

5 We have therefore simplified the structure of the guidance so that it now distinguishes between disclosures for the care of an individual patient, disclosures for the protection of the patient and others, and disclosures for all other purposes.

**Framework and principles**

6 The majority of respondents (81%) thought that the framework section of the guidance was helpful, although some thought it could be improved. The main criticisms were that it was unnecessarily long, that some paragraphs were too densely packed, and that the guidance on the difference between disclosure required and permitted by law was confusing. Some respondents also thought we could make more of the framework as the structuring principle for the rest of the guidance, for example by including the flowchart in this section.

7 In response we have:

- separated out the legal bases for disclosure and the principles of good practice, which now form a separate section, and act as an executive summary for the guidance and align with the Caldicot principles as far as possible
- re-written the guidance on disclosures that are required and disclosures that are permitted by law to make it clearer
- shortened and simplified the paragraphs where possible, especially the sections on public interest disclosures which repeated detailed guidance given elsewhere
- brought forward the flowchart to give it more prominence as a navigation tool.

**Disclosures for direct care**

8 Respondents were generally supportive of the draft guidance in this section, and on all but one question (see paragraph 9 below), between 78% and 88% of respondents agreed with the draft guidance.

9 Respondents’ views were significantly split on one question, however, which concerned the circumstances in which doctors may share information against the wishes of an adult patient who has the capacity to make the decision, when that patient (but no one else) is at risk of harm. This might arise, for example, in cases of domestic abuse or in cases of self-neglect. The question we asked was whether such disclosures could ever
be justified. 59% of respondents answered yes, 28% were unsure, and 13% answered no.

10 The UK legal frameworks generally recognise that adults who have capacity are entitled to make their own decisions, even if those decisions appear to be unwise to others, and even if those decisions may leave them (but no one else) at risk of serious harm. The 2009 confidentiality guidance broadly reflects that position, although it is not absolute: we say that doctors should 'usually' abide by a competent adult’s decision, which leaves open the possibility that there might be circumstances in which the doctor could be justified in overriding it. We don’t currently expand on what those circumstances might be, and we often receive enquiries from doctors who are struggling to understand whether a disclosure might be justified.

11 The consultation responses we received did not give us a clear answer to the question of whether and, if so, when such disclosures could be justified. Even those respondents who thought that there may be circumstances in which disclosure without consent may be justified to protect an adult who has capacity highlighted significant risks with including this in the guidance. These included:

- the potential for doctors to act in a paternalistic fashion, substituting their own judgements for those of patients who have the right to make decisions for themselves
- the risk that the trust that underpins the doctor-patient relationship would be undermined
- the risk that doctors will feel obliged to disclose information, or that our advice could be overused, leading to routine violations of patients’ autonomy and privacy
- concerns about the lawfulness of disclosure, and the need to seek legal advice.

12 Following the consultation, we held a roundtable discussion with representatives from domestic violence charities, the police, lawyers and policy makers to discuss the issue further. While this discussion highlighted many practical issues for doctors and others who work with adults who are at risk for serious harm, it did not take us forward in terms of articulating the circumstances in which disclosure might be justified.

13 We therefore sought advice from leading counsel. Counsel for Northern Ireland advised against going further than we do in the current guidance. Counsel for Scotland said no more than that the disclosure would need to be justified in the public interest. Counsel for England and Wales thought that there may be rare cases in which disclosure could be justified to prevent a serious crime even if no one else is at risk, but said that this is only likely to be justifiable in exceptional circumstances where there is clear evidence of an imminent risk of serious harm to the individual, and where there are no alternative (and less intrusive) methods of preventing that harm. He also recommended that doctors should get legal advice before disclosing on these grounds.
14 In the revised guidance we have followed the advice of Counsel for England and Wales, and have reflected in an endnote the very exceptional circumstances in which disclosure might be justified. This aligns with the advice provided by the BMA and is probably as far as we can go to be helpful in this very complex area.

15 The main issues raised in comments on the rest of the direct care section were as follows.

- **Membership of the direct care team.** Several respondents wanted a clearer definition of the care team and the boundaries of the care team, with some calling for us to be quite specific about who can and can’t be considered part of this team. We do not think it would be appropriate or helpful for our guidance to be prescriptive on this point, given the potential diversity of direct care teams. We have however added a definition of ‘direct care’ which aligns with a definition used within the NHS, to make clear the sorts of purposes that fall within scope of the guidance.

- **Sharing information with friends and family.** In the consultation draft we said that, if a patient wanted a doctor to share information with a particular person or people, then the doctor should abide by the patient’s wishes unless there was a ‘compelling’ reason for not doing so. One respondent asked for an example of what we meant by this and, on reflection, we think that there should be limited circumstances in which it would apply. We have therefore removed this paragraph.

- **Listening to those close to the family.** There was strong support for this section of the guidance, although one of the defence associations pointed out that it should be rare that doctors should be having conversations about patients who have capacity with those close to them without the patient’s knowledge or consent. We have amended the guidance to reflect this.

- **Assessing capacity.** There was a strand of feeling throughout the consultation responses that we should include more detail about assessing capacity and making (and recording) best interests decisions. This is an area of practice that is dealt with in our guidance *Consent* and so we have resisted duplicating that advice in this guidance, but have made the links clearer.

- **Best interests.** A respondent from Scotland highlighted that the term ‘best interests’, which is a concept in mental capacity legislation in England, Wales and Northern Ireland, is not a term that is used in relation to adults in Scotland. This was an oversight on our part, and we have amended the guidance so that it refers to ‘overall benefit’. This is a term that legal counsels have agreed is compatible with all of the legal frameworks across the UK.

**Disclosures for purposes other than direct care**

16 As discussed in paragraphs 2–5 above, we have made the decision in the revised guidance to collapse the distinction between indirect care and non-care purposes. This section of the guidance therefore now covers all disclosures for purposes other than
direct care, except for disclosures for the purpose of protecting the patient or others (see below).

17 As with the direct care section, respondents were generally supportive of the draft guidance and, on all but one question (see paragraph 18 below), between 79% and 94% of respondents agreed with the draft guidance.

18 The one question where there was a lower percentage of agreement (70%) concerned the circumstances in which disclosure of identifiable patient information might be justified in the public interest for health and social care purposes other than public protection. Examples of such purposes include research, management of health and social care services, education and training, and clinical audit. While the majority agreed with the guidance, those who didn’t tended to be bodies with a special interest and expertise in health informatics or governance of use of patient information.

19 The main objections to the draft guidance (which reproduced the policy position in the current guidance) were as follows.

- **The legal basis for public interest disclosures for secondary purposes is uncertain.** The lack of case law on this point led some respondents to conclude that there is no legal or ethical scope for disclosures for purposes other than public protection to be made in the public interest unless the necessary statutory approval has been obtained.
- **We are operating a two-tier public interest test.** Some respondents said that on the one hand, there has to be an identifiable risk of ‘serious harm’ to an individual or society in order to justify the disclosure; on the other a more general public interest justification can be used for disclosures ‘for an important indirect care purpose’.
- **Concerns about doctors acting outside of their competence, and about transparency and fairness.** Several respondents raised questions about the competence of individual practitioners to make public interest decisions for secondary purposes in isolation. One respondent argued that doctors would be in breach of other parts of GMC guidance if they failed to respect existing statutory arrangements, or if they acted outside the limits of their competence. It was also argued that the decisions of the individual practitioner would not be transparent, and therefore not open to challenge. By contrast, bodies such as the Confidentiality Advisory Group (which is the body that considers applications made under section 251 of the *NHS Act 2006*, described below) make their decisions publically available.

20 These objections had considerable force, although we do not agree with all of them.

21 Our view of legal position (which is supported by advice from leading counsel) is that the assessment of whether a public interest disclosure for uses such as research is justified is not intrinsically different in nature to the assessment of whether a disclosure is justified for public protection reasons. In both cases the assessment is whether the disclosure of identifiable information is necessary and proportionate,
taking into account individuals’ and society’s rights and claims to confidentiality and the rights and claims of the whole of society to better health and to protection against threats to ill health. We do however agree that this is an uncertain area of law, and that doctors should seek independent advice on the lawfulness of a disclosure for these purposes.

22 We also agree that, as a matter of good practice, where statutory processes are in place for considering whether disclosure of personal information without consent for health and social care purposes would benefit patients or the public sufficiently to outweigh patients’ right to privacy, then doctors should follow them. This is the case in England, Wales and Northern Ireland, where section 251 of the National Health Service Act 2006 (which applies in England and Wales) and the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 allow the common law duty of confidentiality to be set aside for defined purposes where it is not possible to use anonymised information and where seeking consent is not practicable. There is no comparable framework in Scotland, where such disclosures continue to be justified in the public interest.

23 We have therefore amended the guidance to:

- strengthen the expectation that doctors will use statutory arrangements where they are available
- emphasise that disclosures of identifiable information without consent for secondary purposes should be exceptional
- warn doctors about the uncertainty of the legal position, and the importance of seeking independent advice.

24 The main issues raised in comments on the rest of this section of the guidance were as follows.

- **The validity of the distinction between anonymised and de-identified information.** Several expert respondents recommended that we collapse the distinction between anonymised and de-identified data as it is too nuanced to be of practical assistance, and potentially confusing for doctors. We were urged to adopt the same terminology of the Information Commissioner’s Office, as the authority in this area, which we have done.

- **The process of anonymising or de-identifying information.** Several respondents highlighted problems with our draft guidance on this point. Part of the advice was redundant as it created an irrelevant distinction between temporary and permanent staff, which we have now removed. The advice also confused the legal basis for disclosing information for the purpose of anonymisation with the controls that are necessary to safeguard identifiable or potentially identifiable information while it is being processed. These environmental issues need to be considered separately to the
question of who can anonymise or de-identify confidential information, which the revised guidance now does.

Disclosures for the protection of patients and others

25 As mentioned in paragraph 16 above, in restructuring the guidance we took the decision to create a separate section on disclosure of information for the protection of patients and others. This is a distinct area of practice, and one that doctors frequently ask us for advice about.

26 Respondents were generally supportive of the draft guidance, with significant comments in the following areas.

- **Doctors’ duties in relation to public protection.** Several respondents highlighted the very serious and sometimes tragic consequences that can result when information about patients who pose a serious risk to others is withheld on confidentiality grounds. While we cannot lawfully mandate disclosure in such circumstances (each case must be considered on its particular facts) we agree that our guidance could emphasise more clearly that doctors have public protection responsibilities in addition to their responsibilities to individual patients. We have therefore made this more explicit, and have indicated the circumstances in which doctors ‘should’ disclose information.

- **The definition of ‘serious crime’.** Some respondents asked us to be much more specific about what does, and doesn’t, count as serious crime but this is not something we think we have the remit or authority to determine. Instead we link to the NHS definition (which is given in the NHS confidentiality code of practice). We have however revisited our summary of this definition to make sure that we are summarising it accurately.

- **Expanding the examples of ‘serious harm’.** The draft guidance gave prevention of violent crime as an example of a circumstance in which disclosure of information might be justified in the public interest to prevent death or serious harm. But respondents commented that this is not the only situation in which disclosure might be justified. Other examples of situations in which failure to disclose information may expose others to a risk of death or serious harm include when a patient is not fit to drive, or has been diagnosed with a serious communicable disease, or poses a serious risk to others through being unfit for work. We now include these examples in the guidance.

Managing and protecting information

27 Once again, respondents were generally supportive of the draft guidance, with between 88% and 91% of respondents agreeing with the advice we were giving. The main areas for comments were as follows.

- **Doctors’ duties in relation to information governance and compliance with data protection legislation.** There was a clear majority in favour of including...
guidance for doctors on information governance and compliance with data protection, although respondents also asked us to be clearer about what we expect of all doctors, and what of data controllers specifically. We have amended the guidance to make this clearer.

- **Guidance on improper access and disclosure.** While there was a high level of agreement with the guidance on improper access and disclosure, some concerns were expressed about whether it will be difficult to adhere to in practice. The fact that it may not be practicable to follow the advice in every case is not necessarily a compelling argument for not including the duty, but we have acknowledged in the revised guidance that there are some practice environments in which it may be difficult to avoid conversations with (or about) patients being overheard by others. We have said that doctors should to try to minimise breaches of confidentiality and privacy as far as it is possible to do so in such circumstances.

- **Communication with patients.** In the draft guidance we had said that doctors should 'make sure that patient information is secure when it is stored or transmitted'. Some respondents commented that this was too onerous and could deter doctors from using ordinary commercial email and video conferencing systems to communicate with a patient with that patient's consent. We have amended this section to say that doctors should take reasonable steps to make sure that the communication methods they use are secure (with links to detailed guidance from other bodies). We have also flagged that this is not limited to electronic communications; other communication methods (including letters, and messages on answering machines) also pose some risk of interception.

### Legal annex

28 The inclusion of a legal annex was warmly welcomed by many respondents who found it a very helpful reference in a highly complex area. The only significant concern raised was that it was not clear that the annex adequately reflected the different legal frameworks in the four countries, and a legal body in Scotland called for us to give separate guidance for each of the countries. We decided that it would be unwieldy to do this, so have instead arranged the legal annex thematically and have indicated for each piece of legislation listed its territorial extent.

29 The legal annex up to page 49 has been checked by legal counsel, and the remainder will be reviewed by our in house legal team. Despite the positive reception of the annex we are still considering whether it should remain part of the guidance. We are likely to need to update the annex with some regularity as the law changes, and it may be easier to do this if the annex is published as a separate document.
Explanatory guidance

30 We consulted on seven pieces of explanatory guidance, plus the confidentiality section of our guidance 0-18 years: guidance for all doctors. Only the explanatory statements are considered in this paper; proposed amendments to the 0-18 guidance will be considered when that guidance is reviewed, which is expected to begin next year.

31 Following the consultation we propose to delete two of the explanatory statements.

- We consider that the explanatory statement on disclosures for financial and administrative purposes is redundant as a result of the way we have restructured the core guidance. The relevant text now appears in the core guidance so we propose to withdraw the separate statement.
- We are also considering withdrawing the explanatory statement on reporting gunshot and knife wounds. This piece of guidance sets out a two-step process for alerting the police when a patient presents for care with a gunshot wound, or a knife wound that is not self-inflicted. In the first instance, the guidance says that doctors should call the police when a patient with a relevant injury has arrived for treatment, but that they should not reveal their identity. Further information can be disclosed with consent or if it is justified in the public interest. Emergency care doctors have told us that this two-step approach does not work in practice; it is perfectly clear to police who attend A&E who the victim is and confidentiality is not protected. The police also seem to be largely indifferent to the existence of the guidance as the main impetus for providing it – which was the collection of statistics about violent crime – is now met through standard data flows. We think therefore that this may be a piece of guidance that was of its time, and can be retired. We still need to check this conclusion with key contacts in the four countries though.

32 The main changes to the remaining explanatory statements are summarised below.

Patients’ fitness to drive and reporting concerns to the DVLA or DVA

33 Very few changes to this guidance were suggested during the consultation. We have however made the following amendments.

- Removal of an extra consent step. One of the defence associations pointed out that we had added a ‘new step’ whereby, if a doctor cannot persuade the patient to stop driving or the patient continues to drive against advice, the doctor should seek consent to disclose relevant information to the DVLA or DVA. The respondent was concerned that this additional step could cause unnecessary delays in taking appropriate action to protect the public. We agree, and have replaced this step with advice that doctors should tell patients that they may be under an obligation to tell the DVLA or DVA if the patient continues to drive when not fit to do so.

- Pilots and others in safety critical roles. Some respondents called for us to generalise the guidance to cover individuals who work in safety critical roles, such as pilots, train drivers or people who operate heavy machinery. However people working
in such roles will usually have regular medicals as part of the job and would expect issues around their fitness to fly, drive a train etc to be reported to their regulator or employer. This would not be the case for the average patient/driver, and any issues are likely to be picked up by their GP or specialist. We therefore propose to retain the focus on road users, but to include an endnote that makes clear that the principles apply to drivers and pilots of other kinds of regulated transport, including by rail, water and air.

- **Making records.** The Sheriff in charge of the Fatal Accident Inquiry following the Glasgow bin lorry crash recommended that doctors should maintain notes in such a way as to maximise their ability to identify repeated episodes of loss of consciousness, or altered awareness, in patients who are or may become drivers. The way in which doctors make and access records will be determined to a large extent by the structure and design of the electronic systems that are in place in general practice and other environments, and it is outside our remit and expertise to set standards for the design of such systems. We have however added a reference to record keeping to the revised guidance.

**Disclosing information about serious communicable diseases**

- **34** This guidance was generally well received, but some concerns were raised in the following areas.

- **Disclosing information within the direct care team.** The consultation draft appears to have caused some confusion as some respondents thought the paragraphs on disclosure within the healthcare team also covered disclosures about a patient’s infection status to other patients. That was not the intention, plus we also realised that we were not distinguishing clearly enough between disclosures that may be necessary for the safe care of the patient (for example if dangerous drug interactions are not identified), and disclosures that may be necessary to protect others from risks of infection (for example arising from needlestick or other injuries). We have therefore separated these issues out.

- **Adequacy of universal precautions for preventing transmission of disease.** Some respondents did not agree that it was sufficient to rely on universal precautions to prevent disease transmission and this was a view that was echoed by many doctors at engagement events around the UK. We do not think it is within our remit or expertise to assess the adequacy of universal precautions but, as a matter of law, if a disclosure would not make any difference to the risk of transmission it is unlikely to be justified. We have therefore amended the guidance to make this clearer, while acknowledging that healthcare staff, like everyone else, are entitled to be protected from risks of serious harm.
Disclosing information for employment, insurance and similar purposes

35 Prior to the consultation we expected to receive significant challenge, particularly from occupational health doctors, on this piece of guidance. In fact the reception was better than we expected (most likely because we made some significant changes following the pre-consultation engagement), although we have made amendments in the following areas.

- **Advising patients about the consequences of withholding reports.** In the consultation draft we said that doctors should explain to the patient the potential consequences for them of a decision to withdraw consent for a report to be sent to the commissioner (such as their employer, or insurer). One respondent commented that it was unreasonable to expect a doctor to know in any detail what those consequences might be, and that it would be better if we advised doctors to tell their patients that there may be ‘adverse consequences’ of their decision. We have made this change.

- **Telling commissioners when patients withdraw consent, or do not attend appointments.** It has been a major source of frustration to some occupational health doctors that they feel unable to tell a report commissioner that a patient has failed to attend an appointment, or has withdrawn consent for a report to be disclosed, on the grounds of confidentiality. Doing this seems to be unproblematic as long as no further information is disclosed, so we have included this new advice.

- **Disclosures required by law.** Some respondents sought clarification on the status of disclosures under the *Police Pensions Regulations 2015* and the *Police (Injury Benefit) Regulations 2006*. The question was whether these regulations require doctors who are acting as Selected Medical Practitioners under the regulations to disclose reports to the scheme manager or police pension authority even when the applicant has withdrawn consent. We have considered this, but have come to the conclusion that it is not our role to interpret statutory regulations. We have therefore acknowledged that such regulations can require disclosure of information, but advise doctors to seek independent legal advice if they are unsure of what the law requires.

Disclosing information for education and training

36 In the consultation draft of this guidance, we included advice on reporting adverse incidents. While this was well received by respondents, the task and finish group took the view that the guidance (which applies in a wide range of circumstances) may be missed if we put it in guidance on education and training. We have therefore re-located the advice to the core guidance.

37 The other main changes to this guidance are as follows:

- **Considering medical and other healthcare students as part of the healthcare team.** In the draft guidance we considered the issues relating to students and doctors in training under separate headings, which gave the impression that we did not think that students could be part of the healthcare team. That is not the case, so we have...
redrafted the guidance to distinguish between doctors/students who are, and who are not, providing or supporting direct care.

- **Clarification of guidance on training records and case studies.** While the majority of respondents welcomed the new guidance on training records and case studies, there were also calls for us to differentiate between training records that would be seen by educational supervisors and case studies that would be made public. We have done this, and have also reflected the principle in the core guidance that the risk of re-identification of anonymised data will vary according to the environment in which the information is held.

- **Disclosures about adults who lack capacity for education and training.** In the consultation draft we advised that disclosure of information about patients who lack capacity could be justified for education and training purposes if it was considered to be in the public interest, and ‘not contrary’ to the best interests of the individual. Some respondents were uncomfortable with this advice as they interpreted the ‘not contrary to best interests’ formulation as a proposed legal basis for the disclosure. We did not mean this – we merely meant that the doctor (as a matter of good practice) should have no reason to believe that the disclosure was contrary to the interests of the patient. We have checked this view with legal counsel and have amended the guidance to make the meaning clearer.

**Responding to criticism in the press**

- **38** The only post-consultation change to this guidance has been to make clear that it goes wider than traditional media, and includes criticism that might be made online or on social media.
Membership of the Confidentiality task and finish group

- Professor Jonathan Montgomery, Professor of Health Care Law at the University College London, and Chair of the Nuffield Council on Bioethics and the Health Research Authority (Chair)
- Dr Tony Calland, retired GP and former Chair of the BMA Ethics Committee
- Yvonne Dawkins, community nurse and GMC associate
- Dr Al Dowie, Senior University Teacher in Ethics and Law, Medical and Dental Schools, University of Glasgow
- Bethan George, Deputy Director, Integrated Care, Tower Hamlets Clinical Commissioning Group
- Dr Judith Hulf, Senior Medical Advisor and Responsible Officer, GMC
- Prof Roy McClelland, Professor Emeritus of Mental Health at Queen’s University Belfast and Consultant Psychiatrist at Belfast City Hospital
- Michelle Millar, Disability Action, Northern Ireland [left the group in February 2016]
- Dr Sharon Raymond, Clinical director at Greenbrook Healthcare; Named GP for safeguarding children, Croydon; and medical member of First Tier Social Entitlement Chamber
- Cathie Williams, Chief Officer of Association of Directors of Adult Social Service