



General
Medical
Council

Confidentiality:

a public consultation on our draft guidance

Working with doctors Working for patients

About this consultation

We are consulting on revised guidance for all doctors on confidentiality

Confidentiality is central to the trust between doctors and patients. Patients have a right to expect that information about their health will be kept in confidence by their doctors. But confidentiality is not absolute, and doctors need to strike a balance between protecting confidential patient information and sharing information appropriately.

Our current guidance *Confidentiality* was published in 2009.* Over the past year, we have been reviewing it to make sure that it is clear, helpful, relevant to doctors' needs and compatible with the law throughout the UK. We have also reviewed seven explanatory statements that give more detailed advice on how to apply the principles in the confidentiality guidance to situations that doctors often encounter, or find hard to deal with.

Our guidance is intended mainly for doctors, but it may also help patients, the public and other health and social care staff to understand what they can expect from doctors.

How have we developed the draft guidance?

Over the past year we have gathered information from a range of sources to help us to redraft the guidance. For example:

- we looked at the type of enquiries that we receive about confidentiality-related issues from doctors, patients and others
- we ran surveys for doctors, patients and organisations representing them, and other interested groups, seeking feedback on our current guidance
- we commissioned a literature review[†] looking at patient and public attitudes to confidentiality since 2007 (when the guidance was last reviewed)
- we held two roundtable events for patients to explore their views and expectations about how and why their personal medical information might be disclosed.

The redrafting process was overseen by a task and finish group whose members provided expert input from a range of legal, medical, health, social care and patient perspectives.[‡]

* You can find all of our guidance at www.gmc-uk.org/guidance.

† You can read the literature review at www.gmc-uk.org/about/research/27704.asp.

‡ You can see the membership of the task and finish group at www.gmc-uk.org/confidentialityreview.

Have your say

In this document, we are asking for feedback on the **draft core guidance**, which you can find on our guidance review pages at www.gmc-uk.org/confidentialityreview.

There are **36** questions in this consultation document. You do not have to answer all of the questions if you prefer to focus on specific issues but you do need to have read the draft guidance to answer the questions.

We have also produced two shorter versions of this questionnaire, which you don't need to read the draft guidance to answer. These are:

- a questionnaire with 10 questions, which is mainly aimed at individual patients and members of the public
- a questionnaire with 11 questions, which is mainly aimed at individual doctors and other healthcare professionals.

You can respond to these questionnaires online on our consultation website: <https://gmc.e-consultation.net>. You can also download them from our guidance review pages at www.gmc-uk.org/confidentialityreview. Please contact us at the details below if you would like a printed copy.

How do I take part?

This consultation runs from **25 November 2015** to **10 February 2016**. We welcome responses from anyone who has a view about the draft guidance.

The simplest way to answer the questions is on our consultation website: <https://gmc.e-consultation.net>. You can also answer the questions using the text boxes in this document and send your completed response by:

- email to confidentiality@gmc-uk.org
- post to Standards and Ethics team, General Medical Council, Regents Place, 350 Euston Road, London NW1 3JN.

Please contact us using the details above if you would like a printed copy.

Consultation on explanatory statements

We are separately consulting on **explanatory guidance**, which gives more detailed guidance on specific confidentiality issues such as reporting concerns about patients who may not be fit to drive, disclosing information about serious communicable diseases, and how the principles of confidentiality apply to children and young people.

You can read the explanatory statements and respond to the questions online on our consultation website: <https://gmc.e-consultation.net>. You can also download the consultation document from our guidance review pages at www.gmc-uk.org/confidentialityreview. Please contact us at the details above if you would like a printed copy.

How your responses will help

Your responses will help us to ensure that the guidance we give to doctors is clear, realistic and gives the right advice.

Our remit is UK wide, so our guidance needs to take into account the different healthcare and legal systems of Scotland, Northern Ireland, England and Wales. We welcome feedback on any areas where the guidance could be improved in this respect.

We have carefully considered the aims of the public sector equality duty in developing the guidance. The *Equality Act 2010* identifies nine characteristics that are protected by the legislation.* Responses to this consultation will help us to understand how the principles in the guidance will affect doctors, patients and the public from across the protected characteristics. We therefore welcome your comments on whether any areas from the guidance could be strengthened from an equality perspective.

We also welcome your views about we could illustrate how the guidance should work in practice. In the past we've used case studies (such as those in our interactive learning tool, *Good medical practice in action*[†]), flowcharts and other learning materials to show how the guidance should be interpreted in different situations.

We hope to publish the final version of the guidance in 2016.

* Age, disability, gender reassignment, marriage or civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

† www.gmc-uk.org/gmpinaction

About this guidance, the structure of the guidance, and the framework for considering disclosures (paragraphs 1–35)

The structure of the guidance (paragraph 2)

We have tried to make the guidance easier to follow and apply by structuring it according to the purposes for which doctors might need to disclose confidential patient information.

We have identified three kinds of purpose:

- **direct care purposes** that contribute to an individual patient's diagnosis, care and treatment
- **indirect care purposes** that contribute to the overall delivery of health and social care but which fall outside the scope of direct care (for example health service management, research, education and training)
- **non-care purposes** that are not connected to the delivery of health or social care but which serve wider purposes (for example, public protection, the administration of justice, financial audit or insurance or benefit claims)

1 Do you agree that we should structure the guidance around the three purposes: direct care; indirect care; and non-care purposes?

Yes No Not sure

Comments

The framework for considering when to disclose personal information (paragraphs 14–35)

The framework section provides an executive summary of the guidance which signposts doctors to the relevant section in the rest of the document.

2 Is the framework section helpful?

Yes

No

Not sure

Comments

3 Do you have any other comments on paragraphs 1–35?

Yes

No

Comments

Direct care uses and disclosure (paragraphs 36–80)

Implied consent to disclose information for direct care purposes (paragraphs 36–45)

This section sets out the circumstances in which we think a doctor can reasonably assume that a patient would want relevant information about them to be shared for their direct care without being directly asked.

It includes, at paragraph 38, a list of conditions which should be met in order for a doctor to rely in a patient's implied consent. These are:

- the person accessing or receiving the information is providing or supporting the patient's direct care
- information is readily available to patients explaining how their information will be used, and that they have the right to object
- the patient has not objected
- anyone to whom the patient's personal information is disclosed understands that it is given in confidence, which they must respect.

4 Do you agree that a doctor should be able to rely on a patient's implied consent to share information about their direct care when all of these conditions are met?

Yes

No

Not sure

Comments

Clinical audit (paragraphs 46–48)

In the revised guidance we say that doctors can rely on implied consent to disclose information for clinical audit if it is to be carried out by members of the team that provided direct care to the patient. If the clinical audit is to be carried out by anyone else then the information should be anonymised or de-identified (which we define in the glossary of the guidance), or the patient should be asked for explicit consent.

This is also the position in the current guidance.

5 Do you agree with the advice about disclosing information for clinical audit?

Yes No Not sure

Comments

Sharing information with, and receiving information from, those close to the patient (paragraphs 49–57)

The guidance highlights the significant role that those close to a patient can play in supporting and caring for them, and the importance of acknowledging that role. It reminds doctors that they:

- must be considerate, sensitive and responsive in giving a patient's friends and family information and support, while respecting the patient's wishes (where they are known or can be found out)
- should not refuse to listen to the concerns of family or friends on grounds of confidentiality, although they should take care not to disclose confidential information unintentionally during such conversations. Doctors should also consider whether the patient would think it would be a breach of trust for them to listen to the views or concerns of others
- must respect the patient's wishes about what information is disclosed to family and friends if the patient is able to make their own decisions, unless the disclosure

can be justified in the public interest (for example, because failure to share the information would leave someone at risk of death or serious harm)

- must act in the best interests of patients who do not have capacity to decide for themselves.

6 Do you think that this section strikes the right balance between being sensitive and responsive to those close to a patient, while respecting the patient’s right to confidentiality?

Yes No Not sure

Comments

Disclosing information about patients who may be at risk of serious harm and who lack capacity to consent (paragraphs 73–75)

At paragraph 74, we have extended the existing duty to tell an appropriate authority when a patient who lacks capacity may be experiencing, or at risk of, abuse or neglect, so that it covers all forms of serious harm.

7 Do you agree with the extension of the duty to disclose information about patients who may be at risk of serious harm and who lack capacity to consent?

Yes No Not sure

Comments

Disclosing information to protect patients who have capacity without their consent (paragraphs 76–80)

It is a general principle in our guidance that adults who have capacity are entitled to make decisions in their own best interests, even if those decisions leave them (but nobody else) at risk of death or serious harm.

However, at paragraph 80 of the draft guidance, we suggest that there may be a public interest justification – in exceptional cases – for disclosing information about an adult who has capacity without their consent, even when nobody else is at risk of serious harm.

For example, we say that this may apply when there are particular duties on the state to protect patients from self-harm when they are detained in prison, in hospital or elsewhere.

8 Do you think that there may be circumstances in which there is a public interest justification for disclosing information about an adult who has capacity without their consent, even when nobody else is at risk of serious harm?

Yes No Not sure

9 What do you think would be the consequences of us changing our advice in this way?

Comments

10 Do you have any other comments on the 'direct care uses and disclosure' section of the guidance (paragraphs 36–80)?

Please note that we have not asked questions about paragraphs that are substantially unchanged from the current guidance, but we do welcome comments on those paragraphs.

Yes

No

Comments

Indirect care uses and disclosure (paragraphs 81–109)

Anonymised and de-identified information (paragraphs 81–89)

We have included new guidance on using anonymised and de-identified information for indirect care purposes, for example healthcare management, research and commissioning.

11 Is the guidance on using anonymised and de-identified information helpful?

Yes

No

Not sure

Comments

The process of anonymising or de-identifying information

At paragraph 88 we say that, where patient information cannot be anonymised or de-identified by members of the team providing or supporting the patient's direct care, the information can be anonymised or de-identified by:

- staff temporarily brought in to provide or support the patient's direct care, or
- in a secure environment that is capable of processing the information securely, with suitable contracts and agreements.

12 Do you agree with this guidance on the process of anonymising or de-identifying information?

Yes

No

Not sure

Comments

Public interest justification for indirect care uses (paragraphs 100–106)

We say (at paragraph 100) that, where there are statutory arrangements for considering the disclosure of identifiable information for indirect care purposes (such as those provided by section 251 of the *NHS Act 2006*) there is likely to be very limited scope for justifying such a disclosure in the public interest.

13 Do you agree with this statement about the very limited scope for justifying disclosure in the public interest of identifiable information for indirect care purposes?

Yes No Not sure

Comments

We have expanded the advice on disclosing information for indirect care uses in the public interest. At paragraph 104, we list five factors that doctors must consider before making a decision.

- the potential harm or distress to patients arising from the disclosure (for example, in terms of their future engagement with treatment and their overall health)
- 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)

- the potential harm to others (whether to a specific person or the public more broadly) if the information is not disclosed
- the potential benefits to an individual or society arising from the release of the information
- whether the harms can be avoided or benefits gained without intruding into patients' privacy and if not, what is the least significant intrusion.

We list the same factors later in the guidance (at paragraph 125) for doctors who are considering disclosures in the public interest for public protection reasons.

14 Do you agree that these are the factors that doctors should take into account when considering whether a disclosure is justified in the public interest?

Yes No Not sure

Comments

15 Do you have any other comments on the 'indirect care uses and disclosure' section of the guidance (paragraphs 81–109)?

Please note that we have not asked questions about paragraphs that are substantially unchanged from the current guidance, but we do welcome comments on those paragraphs.

Yes No

Comments

Non-care uses and disclosure (paragraphs 110–132)

Requests for information from employers, insurers, government bodies and others (paragraphs 110–114)

The guidance in this section has not changed significantly from the current guidance, although we have amended the explanatory statement *Disclosing information for employment, insurance and similar purposes*.

You can respond to a separate survey on that explanatory statement online on our consultation website: <https://gmc.e-consultation.net>. You can also download the consultation document on the explanatory statements from our guidance review pages at www.gmc-uk.org/confidentialityreview, or contact us if you would like a printed copy. Our contact details are at the start of this document.

Disclosures to the courts or in connection with litigation (paragraphs 118–121)

The guidance on disclosing information to the courts and in connection with litigation has not changed significantly from that in the current guidance. However, we have included new advice that doctors should:

- tell the courts if they think that disclosure of information might put someone at risk of harm (paragraph 118)
- cooperate with the system of precognition in Scotland (paragraph 120).

16 Do you agree with this advice on disclosing information to the courts and in connection with litigation?

Yes No Not sure

Comments

Disclosures in the public interest (paragraphs 122–128)

We have retained the current guidance on disclosing information without consent in the public interest, for example for public protection purposes.

We have however expanded the guidance on the factors that doctors must consider before making a decision. These are listed in question 14 of this survey and at paragraph 125 of the draft guidance.

17 Is the guidance on disclosing information in the public interest at paragraphs 122–128 helpful?

Yes No Not sure

Comments

18 Do you have any other comments on the ‘non-care uses and disclosures’ section of the guidance (paragraphs 110–132)?

Please note that we have not asked questions about paragraphs that are substantially unchanged from the current guidance, but we do welcome comments on those paragraphs.

Yes No

Comments

Managing and protecting personal information (paragraphs 133–156)

Knowledge of information governance and compliance with data protection legislation (paragraphs 134–139)

In the revised guidance we advise doctors that they must:

- develop and maintain an understanding of information governance that is appropriate to their role (paragraph 134)
- be familiar with, and follow, the confidentiality, data protection and record management policies and procedures where they work and know where to get advice on these issues (paragraph 134)
- understand and meet their obligations under the *Data Protection Act 1998* (where they are data controllers under the terms of the Act) (paragraph 137)
- process patient information fairly and be open with patients about how their information will be used, accessed and disclosed (paragraph 138).

These duties are implicit in our current guidance but, in our discussions before the consultation, respondents told us it would be helpful to make them explicit.

19 Do you agree with the inclusion of these duties on information governance and compliance with data protection legislation?

Yes No Not sure

Comments

Improper access and disclosure (paragraphs 140–143)

In response to feedback from doctors, employers and patients and the findings of the literature review, we have expanded the description of the circumstances in which a patient's confidentiality may be breached unintentionally. Reception areas and ward rounds are areas of particular concern for patients.

20 Do you agree with the guidance on improper access and disclosure?

Yes No Not sure

Comments

Records management (paragraphs 144–148)

There are new requirements at paragraph 148 for doctors who have responsibilities for managing or recruiting staff, to make sure that:

- staff are suitably trained
- employment contracts contain appropriate obligations in relation to confidentiality and data protection.

21 Do you agree with the inclusion of these duties for doctors who have responsibilities for managing or recruiting staff?

Yes No Not sure

Comments

Disclosing information after a patient has died (paragraphs 152–156)

We have re-ordered the guidance on disclosure after a patient has died, to clarify what is mandatory (paragraph 153) and what is a matter for professional judgement (paragraph 154).

22 Do you agree with the guidance on disclosing information after a patient has died?

Yes No Not sure

Comments

23 Do you have any other comments on the 'managing and protecting personal information' section of the guidance (paragraphs 133–156)?

Please note that we have not asked questions about paragraphs that are substantially unchanged from the current guidance, but we do welcome comments on those paragraphs.

Yes No

Comments

Glossary, legal annex, endnotes and flowchart

Glossary

The glossary defines key terms used in the guidance.

24 Do you have any comments on the glossary?

Yes

No

Comments

Legal annex

In this section, we aim to provide an outline of law that is most commonly encountered by, or that poses most challenge to, individual doctors.

The annex also covers some organisational duties where these are likely to be relevant, but does not cover law relating to children and young people as this is covered in our guidance *0–18: guidance for all doctors*.

25 Is the legal annex helpful?

Yes

No

Not sure

Comments

26 Do you think there are any inaccuracies or important omissions from the legal annex?

Yes No Not sure

Comments

Endnotes

27 Do you have any comments on the endnotes?

Yes No

Comments

Flowchart

On the back cover of the draft guidance we have included a flowchart that is intended to help doctors to structure their decision making in relation to disclosing information.

28 Do you think this is helpful?

Yes No Not sure

Comments

Developing the guidance and associated materials

29 Overall, how clear is the draft guidance?

Very clear Fairly clear Not very clear Not clear at all Not sure

Please give reasons for your response

30 Is there anything missing from the guidance?

Yes No Not sure

If yes, please give details below

31 Is there anything you think should be removed from the guidance?

Yes No Not sure

If yes, please give details below

32 To help show how the guidance might work in practice, we will develop case studies that feature specific challenges faced by doctors and patients.

Are there any issues or situations that you think it might be useful to have a case study on?

Yes No Not sure

Please give details below

33 Do you have any other ideas on how we could show how the guidance might work in practice, such as guidance for patients or interactive flowcharts?

We are particularly interested in examples of innovative formats that you use or are aware of and that you think would work well in this area.

Yes No Not sure

If yes, please give details

Equality

The *Equality Act 2010* identifies nine groups of people who share characteristics that are protected by the legislation. These are referred to as protected characteristics. They are:

- age
- disability
- gender reassignment
- marriage or civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation.

We have carefully considered the aims of the public sector equality duty in developing this guidance.

34 Do you think any part of the guidance will affect people with protected characteristics that are covered by equality legislation? This could include doctors, patients and members of the public.

Yes No Not sure

If you answered yes to the question above, please tell us which parts of the guidance and what you think the impact might be.

The consultation process

To help us continue to improve the way we consult, please tell us about your experience of taking part in this consultation.

35 Did you find the consultation documentation (the questionnaire and any associated instructions if completing it online) clear and easy to use?

Yes No Not sure

If you have answered no, or are not sure, please tell us why.

36 We used different presentation formats for the consultation drafts of the core guidance and the explanatory statements. Did you prefer one format over the other?

Yes No Not sure

If you answered yes, please tell us why.

Thank you for taking the time to give us your comments.

Please tell anyone you think might be interested in responding to this consultation.

The final section asks for some information about you to help us to analyse the responses.

About you

Finally, we'd appreciate it if you could give some information about yourself to help us analyse the consultation responses.

Your details

Name

Job title (if responding as an organisation)

Organisation (if responding as an organisation)

Address

Email

Contact telephone (optional)

Would you like to be contacted about our future consultations?

Yes

No

If you would like to know about our upcoming consultations, please let us know which of the areas of our work interest you:

Education

Standards and ethics

Fitness to practise

Registration

Licensing and revalidation

Data protection

The information you supply will be stored and processed by the GMC in accordance with the *Data Protection Act 1998* and will be used to analyse the consultation responses, check the analysis is fair and accurate, and help us to consult more effectively in the future. Any reports published using this information will not contain any personally identifiable information. We may provide anonymised responses to the consultation to third parties for quality assurance or approved research projects on request.

The information you provide in your response may be subject to disclosure under the *Freedom of Information Act 2000* which allows public access to information held by the GMC. This does not necessarily mean that your response will be made available to the public as there are exemptions relating to information provided in confidence and information to which the *Data Protection Act 1998* applies. Please tick if you want us to treat your response as confidential.

Responding as an individual

Are you responding as an individual?

Yes No

If yes, please complete the following questions. **If not, please complete the 'responding as an organisation' section on page 32**

Which of the following categories best describes you?

- Doctor Medical educator (teaching, delivering or administering)
- Medical student Member of the public
- Other healthcare professional
- Other (please give details) _____

Doctors

For the purposes of analysis, it would be helpful for us to know a bit more about the doctors who respond to the consultation. If you are responding as an individual doctor, could you please tick the box below that most closely reflects your role?

- General practitioner Consultant
- Other hospital doctor Doctor in training
- Medical director Other medical manager
- Staff and associate grade (SAS) doctor
- Sessional or locum doctor Medical student
- Other (please give details) _____

What is your current practice setting? (Please tick all that apply)

- NHS Independent or voluntary Other

What is your country of residence?

- England Northern Ireland Scotland Wales
- Other – European Economic Area
- Other – rest of the world (please say where) _____

To help make sure our consultations reflect the views of the diverse UK population, we aim to monitor the types of responses we receive to each consultation and over a series of consultations. Although we will use this information in the analysis of the consultation response, it will not be linked to your response in the reporting process.

What is your age?

- 0–18 19–24 25–34 35–44
 45–54 55–64 65 or over

What is your gender?

- Female Male

Do you have a disability, long-term illness or health condition?

- Yes No Prefer not to say

The *Equality Act 2010* defines a person as disabled if they have a physical or mental impairment, which has a substantial and long-term (ie has lasted or is expected to last at least 12 months) and adverse effect on the person’s ability to carry out normal day-to-day activities.

Which of the following options best describes your sexual orientation?

- Bisexual Gay man Gay woman/lesbian
 Heterosexual/straight Prefer not to say
 Other (please give details) _____

What is your ethnic group? (Please tick one)

Asian or Asian British

- Bangladeshi Chinese Indian Pakistani
- Any other Asian background (please specify) _____

Black, African, Caribbean, black British

- African Caribbean
- Any other black, African or Caribbean background (please specify) _____

Mixed or multiple ethnic groups

- White and Asian White and black African White and black Caribbean
- Any other mixed or multiple ethnic background (please specify) _____

Other ethnic group

- Arab
- Any other ethnic group (please specify) _____

White

- British, English, Northern Irish, Scottish or Welsh
- Irish Gypsy or Irish traveller
- Any other white background (please specify) _____

Responding as an organisation

Are you responding on behalf of an organisation?

- Yes No

If yes, please complete the following questions. **If not, please complete the 'responding as an individual' section on page 29.**

Which of the following categories best describes your organisation?

- | | |
|--|---|
| <input type="checkbox"/> Body representing doctors | <input type="checkbox"/> Body representing patients or the public |
| <input type="checkbox"/> Government department | <input type="checkbox"/> Independent healthcare provider |
| <input type="checkbox"/> Medical school (undergraduate) | <input type="checkbox"/> Postgraduate medical institution |
| <input type="checkbox"/> NHS or HSC organisation | <input type="checkbox"/> Regulatory body |
| <input type="checkbox"/> Other (please give details) _____ | |

In which country is your organisation based?

- | | | |
|---|----------------------------------|---|
| <input type="checkbox"/> UK wide | <input type="checkbox"/> England | <input type="checkbox"/> Northern Ireland |
| <input type="checkbox"/> Scotland | <input type="checkbox"/> Wales | |
| <input type="checkbox"/> Other – European Economic Area | | |
| <input type="checkbox"/> Other – rest of the world (please say where) _____ | | |

Email: gmc@gmc-uk.org
Website: www.gmc-uk.org
Telephone: **0161 923 6602**

Standards and Ethics Section, General Medical Council, 350 Euston Road, London NW1 3JN.

Textphone: **please dial the prefix 18001** then
0161 923 6602 to use the Text Relay service

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Published November 2015

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