



Decision making and consent:

a public consultation on
our guidance

Full questionnaire

Consultation runs: 24 October 2018 to 23 January 2019

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At the end of the consultation process, we will publish reports explaining our findings and conclusions. We won't include any personally identifiable information in these reports, but may include illustrative quotes from consultation responses. We may also provide responses to third parties for quality assurance or to approved research projects, which are anonymised before disclosure where possible.

Freedom of information

Your response to this consultation may be subject to disclosure under the *Freedom of Information Act 2000*, which allows public access to information we hold. This doesn't necessarily mean your response will be made available to the public as there are exemptions relating to information given in confidence and information to which the General Data Protection Regulation applies.

Would you like your response to be treated as confidential?

Yes No

If yes, please also tell us why:

*www.gmc-uk.org/privacy_policy.asp

Consultation summary

We're updating our guidance on decision making and consent

We're consulting on our revised guidance for doctors on decision making and consent which explains the good practice principles for making decisions about care.

We've worked with a group of doctors, patients, and other health and care professionals to update our guidance, to make sure it's still clear, relevant, consistent with the law across the UK and structured in a way that's easy for doctors to refer to and use.

We're now consulting on the revised guidance and welcome your feedback.

How do I take part?

We welcome responses from anyone with a view on the draft guidance. We've developed this questionnaire for medical and lay professionals who have a detailed working knowledge of the policy, practice and law around consent. **You'll need to read the guidance to complete it.**

We've also developed short versions of this questionnaire for respondents who may not have time to review the guidance in detail:

- **Short questionnaire for doctors, other healthcare professionals** and anyone with a detailed working knowledge of the issues.
- **Short questionnaire for patients, carers and members of the public** with views on decision making and consent.

You can access the questionnaires and the draft guidance on our [consultation website](#)^{*} and respond online or download the questionnaire and send your completed response by:

- email to gmcconsent@gmc-uk.org or
- post to Consent consultation, Standards and Ethics Team, General Medical Council, Regents Place, 350 Euston Road, London NW1 3JN.

You can also ask for print versions of the guidance and questionnaires using these contact details. If you need these documents in Welsh, or in another format or language, call us on 0161 923 6602 or email us at marketingcommunications@gmc-uk.org.

^{*} www.gmc-mpts.smartconsultations.co.uk is our consultation website. You must register to take part in a consultation, but can then respond to all future consultations using your log in details.

Background

Good communication and decision making are at the heart of the doctor-patient relationship. But we know it can be challenging to get it right.

Our current *Consent* guidance* (originally published in 2008) explains the good practice principles for making decisions about care, from the treatment of minor conditions to major interventions with significant risks or side effects.

Our guidance applies to all doctors registered with us, whatever their grade, specialty or UK location, so it is necessarily high level. It is important that it represents common ground between the profession, public and service providers, established through extensive consultation. It must also reflect how individual patients, carers and members of the public experience healthcare - particularly those with unequal access to care or with significant needs, such as patients with impaired capacity.

What's in scope?

We explain the principles of consent and decision making in a few pieces of our explanatory guidance and we'll make sure all references are consistent. But the focus of this review is our core guidance document [*Consent: patients and doctors making decisions together \(2008\)*](#).

Guidance on consent to share information is out of scope for this review as it's addressed in [*Confidentiality: good practice in handling patient information \(2017\)*](#). These pieces of guidance are also out of scope:

- [*0–18 years: guidance for all doctors \(2007\)*](#)
- [*Consent to research \(2010\)*](#)
- [*Treatment and care towards the end of life: decision making \(2010\)*](#)
- [*Good practice in prescribing and managing medicines and devices \(2013\)*](#)

While our *0–18 years* and *Consent to research* guidance are not in scope for this review, you can share any feedback on these publications (see question 17, 'overall comments') and we will take this into account in any future reviews.

* You can read the existing Consent guidance along with all our ethical guidance at www.gmc-uk.org/ethical-guidance

What have we done so far?

We've gathered evidence through our own and [commissioned research](#)^{*} as well as engagement, to understand what issues to address. We've redrafted our guidance to:

- focus on how doctors can support patient decision making and involve patients in decisions about their care as far as possible
- focus on the importance of doctors finding out what is meaningful for their patients and helping them explore the different options
- include practical suggestions and examples to explain how the principles apply
- make it more accessible by referring less to the law and more to the principles on which the law is based.

You can read more about the review on our [website](#).[†]

Putting the principles into practice

We develop learning materials to show how our guidance applies in practice. This includes our [mental capacity decision support tool](#)[‡] and interactive scenarios in [Good medical practice in action](#)[§]. We welcome views on what other topics or issues we could cover in these materials and have asked for your suggestions.

Equality and diversity

We carry out an equality analysis as we develop our guidance to identify the steps we must take to comply with the three aims of the public sector equality duty under the *Equality Act 2010*. Your responses help us understand how our guidance might impact on doctors, patients and members of the public who share protected characteristics.^{**} We ask for diversity information from respondents to help us understand if any groups have raised specific issues about our guidance. This information helps us consider what steps we might need to take to reflect the issues raised.

* www.gmc-uk.org/about/what-we-do-and-why/data-and-research/research-and-insight-archive/doctors-attitudes-to-consent-and-shared-decision-making

† www.gmc-uk.org/about/get-involved/consultations/review-of-our-consent-guidance

‡ www.gmc-uk.org/ethical-guidance/learning-materials/mental-capacity-tool

§ www.gmc-uk.org/ethical-guidance/learning-materials/good-medical-practice-in-action

** The nine protected characteristics under the *Equality Act 2010* are race, disability, age, sex, gender reassignment, sexual orientation, religion and belief, pregnancy and maternity and marriage and civil partnership.

Purpose

What are we asking for your views on?

There are 22 questions in total (17 on the guidance and the rest about the wider consultation process) and some questions asking about you. While you don't have to answer all of them, your views are important, so please complete as many as you can.

We believe these issues in the guidance will be of most interest to you (though you can of course tell us about any aspect of this guidance update too):

- about the guidance, scope and application (question 1)
- summary of the main principles (question 2)
- how decisions are made (including the decision making framework and responsibility and delegation) (questions 3-4)
- guidance on supporting patient decision making (sharing information, maximising ability to make a decision, assessing and explaining benefits and harms, time and when patients don't want to be involved) (questions 5-9)
- guidance on making a decision (expressions of consent, planning future care, making sure patient decision making is voluntary, assessing capacity, assessing the overall benefit of different options, the scope of treatment in emergencies and if you have legal authority to make a decision to protect the patient or other people) (questions 10-16)
- overall comments on the guidance, including anything we haven't specifically asked about (question 17)
- putting the principles into practice (question 18)
- equality and diversity consideration (question 19)
- the consultation documentation and process (20-22)
- and finally, some information about you.

We aim to publish a final version of the guidance in 2019, but the date depends on the outcomes of this consultation.

About the guidance, scope and application

We've revised and restructured our guidance to make it easier for doctors to find the information they need and to make sure it's as clear and helpful as possible about what's expected of doctors when supporting patients to make decisions.

Revised structure

Our current *Consent* guidance (published in 2008) is in three main parts: Principles; Making decisions about investigations and treatment and Capacity issues. There are now two main sections introduced by explanatory text, which doesn't form part of the main guidance, on:

- applying the principles in the guidance
- the relationship between this guidance and action against a doctor's registration
- the scope of the guidance
- the ethical and legal framework which underpins the guidance, and
- the main principles.

Part 1 of the guidance, *Supporting patient decision making*, covers the importance of supporting patients to make decisions and the steps that doctors should take to do this. We've brought some of the information about maximising capacity into this section, to highlight the importance of helping all patients to make decisions, not just those whose capacity is in doubt.

Part 2 of the guidance, *Making decisions*, covers:

- where your patient is able to make the decision and give consent
- where your patient may lack the capacity to make the decision
- where you have legal authority to make a decision to protect the patient or other people
- recording decisions
- reviewing decisions.

We'd welcome your views on whether the revised structure is helpful.

Applying the principles and the relationship between this guidance and action against a doctor's registration

We've revised and expanded the explanation of how our guidance should be applied, to confirm that our guidance is not a rulebook and doctors must use their professional judgement when applying the principles in practice.

And to clarify when the GMC will take action to investigate concerns about fitness to practise, we now explain in this section that there is no automatic link between failure to follow our guidance and a doctor's registration.

We'd like your views on the amended explanation of how the guidance applies.

The scope of the guidance

We've removed the paragraphs on *Involving children and young people in making decisions* from the body of the guidance and instead made it clear in the *Scope of the guidance* where to find this information. This is because many of the principles in our guidance are relevant to decision making with young people, we have detailed guidance on this in [0–18 years: guidance for all doctors](#).*

In this section, we've also confirmed that the same good practice principles apply:

- in the same way to decisions about mental and physical health (to confirm the equal status of these decisions, we've made this explicit in our guidance)
- whether doctors communicate with patients face to face or remotely (eg by telephone or online).

We'd like your views on the scope of this guidance.

The ethical and legal framework

Our guidance takes account of, and is consistent with, the law in all four countries of the UK. It's written to make sure doctors who follow it are acting within the law.

As the legal framework is complex, and in light of concerns about the extent of ethical and legal obligations following recent case law, we've added a section explaining the legal and ethical principles that underpin our guidance. This section is supplementary to the main guidance, so doesn't include any '*must*' or '*should*' statements. It's for anyone who wants to understand the framework and our approach.

* Read the guidance at www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years

In this update we've also removed references to legal cases in the guidance. Instead, we focus on explaining the principles that arise from legal cases, and what they mean for doctors. Doctors, and others who want to know the case law, can refer to the legal annex which we will also update to make sure it remains accurate and helpful.

We'd like your views on this approach and on the usefulness of the legal annex.

1 Comments on scope and application

Main principles of the guidance

We've included a summary of the principles at the beginning of the guidance so doctors and others can see what's expected, before looking at the detailed guidance. We'd like your feedback on whether it's helpful to include a summary. When considering this, please also let us know if these are the right principles to include.

2 Is the summary helpful?

Yes No Not sure

Comments

How decisions are made (paragraphs 1-8)

Decision-making frameworks (paragraphs 1-2)

We've introduced this section to highlight the different approaches to making decisions where:

- a patient is able to make a decision and give or withhold their consent; or
- a patient doesn't have capacity to give or withhold their consent; or
- a doctor has legal authority to make a decision about a patient to protect them or the public.

We've done this to clarify the circumstances in which a decision might rest on consent or another legal authority on which to provide care and direct the reader to relevant guidance on *Making a decision* (paragraphs 39-102).

3 Is it helpful to include these frameworks?

Yes No Not sure

Comments

Responsibility and delegation (paragraphs 3-8)

In this section we explain how the high level guidance in [Good medical practice](#) and our [explanatory guidance on this](#)* applies when doctors delegate the responsibility for discussing treatment options with patients. As this is an area that doctors have told us they would like more advice on, we've outlined the requirements and considerations for delegation. We've also explained what we expect of those to whom this responsibility is delegated.

4 Is the guidance on delegation helpful?

Yes No Not sure

Comments

* See [Good medical practice](#) (paragraphs 15c, 44a and 45) and our explanatory guidance [Delegation and referral \(2013\)](#) which expands on these principles.

Part 1: Supporting patient decision making (paragraphs 9-38)

Doctors and patients sharing information (paragraphs 11-19)

The legal expectation for information sharing has changed following the decision in *Montgomery v Lanarkshire* [2015] and we know that doctors are concerned about whether they're meeting the requirements to share information with patients in a way that will support good decision making.

But we also know that many doctors do this well, even with time and resource constraints, so we've amended the guidance to make it clearer what doctors can do to overcome the barriers to good information sharing. For example, we've emphasised throughout our guidance that doctors should tailor their approach to take into account the needs of each individual patient and draw on additional support where possible, which could include the wider health and care team.

We've also emphasised the importance of listening to patients, as this will help the patient feel involved and minimise the risk of missed information about what the patient wants or needs. We've therefore changed the level of the obligation on doctors from 'should' to 'must' at paragraph 11, to reflect the fact that listening to patients is an overriding duty (see *Applying the principles*).

5 Is the guidance on sharing information helpful?

Yes No Not sure

Comments

Paragraph 16 of our current *Consent* guidance says doctors shouldn't withhold information necessary for making decisions unless they believe that giving it would cause the patient serious harm. This is known as the therapeutic exception. The exception was confirmed in the judgement in the *Montgomery v Lanarkshire Health Board* [2015] case, which said a doctor could withhold information about risk from a patient if they 'reasonably considered that its disclosure would be seriously detrimental to the patient's health.' But the court was clear this is a limited exception to the general principle that patients should be given the information they need to make a decision.

The feedback we've received is that the exception is so limited that it's unhelpful to include it in the main body of the guidance. So we've redrafted the guidance to emphasise the importance of considering the time and way in which information is shared (paragraphs 18 and 19), and we've moved the reference to the exception into a footnote, which directs readers to the legal annex.

6 Do you agree with this approach?

Yes No Not sure

Comments

Maximising your patient's ability to make a decision (paragraphs 20-24)

We've moved and restructured this section to emphasise the principle that it's important to maximise a patient's ability to make decisions in all cases, not just when the patient's capacity is in doubt. At paragraph 23, we've listed the steps doctors can take to maximise a patients' ability to make their own decisions about their care.

7 Is the guidance at paragraphs 20-24 helpful?

Yes No Not sure

Comments

Assessing and explaining benefits and harms (paragraphs 25-30)

Doctors and others ask us about how best to assess benefits and harms and explain them to patients. Our advice focuses on the need to understand the individual patient's priorities and wishes and provide information which takes into account the patient's particular level of knowledge.

While the principles in this update haven't changed, we've updated the language and now refer to risks of harms and potential benefits rather than 'risks and benefits'. This is because risks and benefits are not equivalent. A risk is the probability of a particular (negative) outcome happening, while a benefit is itself an outcome. We feel this is a clearer way of explaining that doctors should explore the extent and the likelihood of both positive and negative outcomes occurring with their patients.

8 Is the guidance on benefits and harms helpful?

Yes No Not sure

Comments

When patients do not want to be involved (paragraphs 33-35)

During our research and pre-consultation engagement, doctors told us that they can feel unsure of their role in circumstances where patients don't want to be involved in decisions about their health and care.

So in this section we've explained the steps that doctors should take if patients don't want to be involved. This includes for example, doctors and the health and care team (where appropriate with relatives/carers) exploring the reasons for the objection and whether there is anything that can be done to reassure and support the patient.

9 Are paragraphs 33-35 helpful?

Yes No Not sure

Comments

Part 2: Making a decision (paragraphs 39-102)

Where your patient is able to make the decision and give consent (paragraphs 39-65)

Expressions of consent (paragraphs 45-50)

We've updated the guidance to include more specific references to the ways patients can express consent (eg non-verbal cues). We also emphasise that, while written consent may be a legal requirement in some cases, doctors should focus more on the quality of the dialogue leading to the decision than on how consent is expressed.

10 Is the guidance on expressions of consent helpful?

Yes No Not sure

Comments

Planning future care (paragraphs 53-60)

In our current *Consent* guidance, the 'Advance care planning' section focuses on situations where a patient may have a life-limiting condition or is facing a situation where loss or impairment of capacity is likely.

In this update, we've changed the title of this section and broadened the scope to highlight the many situations where thinking about care options in advance can be helpful. We've also given some examples of this.

11 Is the guidance on planning future care helpful?

Yes No Not sure

Comments

If you are concerned that a patient may not be able to make a decision freely (paragraphs 61-65)

This is another issue doctors and others ask for advice on, so we've updated the guidance with more examples of the factors that can affect decision making. We've also included more advice on the steps doctors should take if patients are under pressure to proceed with an intervention.

12 Is the guidance at paragraphs 61-65 helpful?

Yes No Not sure

Comments

Where your patient may lack the capacity to make the decision (paragraphs 66-91)

Assessing capacity (paragraphs 72-78)

We've made it clearer that in cases where a patient may lack capacity, it isn't necessary to make decisions immediately. We've also outlined the steps that doctors should take and the factors they should weigh up before making a final decision about capacity.

We know this is an area some doctors find difficult, so we welcome feedback on our draft guidance and will explore with doctors and others during the consultation if there is anything else we could say, or if there are any resources we could signpost or develop, that would be helpful.

13 Is the guidance on assessing capacity helpful?

Yes No Not sure

Comments

Assessing the overall benefit of different options (paragraphs 79-85)

We've updated this section to be explicit about what we expect of doctors and to make sure the guidance reflects practice and law across the UK.

As our guidance applies across the UK, when there are different legal terms used in different countries, we believe it's clearer to use a broader term that has the same meaning across all the countries. So in our current *Consent* guidance, we use 'overall benefit' to describe the ethical basis for decisions about treatment and care for adult patients who lack capacity to decide. This would for example be consistent with the term 'best interests' in England and Wales. However, we want to make sure the guidance is clear and won't cause confusion, so want to test if this approach remains helpful.

14 Should use the term 'overall benefit'?

Yes No Not sure

Comments

The scope of treatment in emergencies (paragraphs 90-91)

We've emphasised the importance of considering capacity even in emergency situations and clarified that while the presumption of capacity still applies, the steps that can be taken to maximise capacity in an emergency situation may be limited.

In some circumstances it may be immediately clear that the patient does not have capacity, but in others, the patient may be able to be involved in the decision. The principle remains that it's important to involve patients in the decisions about their care as far as practicable, even in emergency situations.

15 Is the guidance on emergencies clear?

Yes No Not sure

Comments

Where you have legal authority to make a decision to protect the patient or other people (paragraphs 92-95)

We've included this new section to emphasise that while these circumstances will be limited, doctors must follow the law and codes of practice that apply. And they must seek advice if they have any doubts about the extent of their interventions.

As this is new guidance, we want to make sure it's helpful to doctors who will have to make these decisions in practice, so would like your views on this.

16 Are paragraphs 92-95 helpful?

Yes No Not sure

Comments

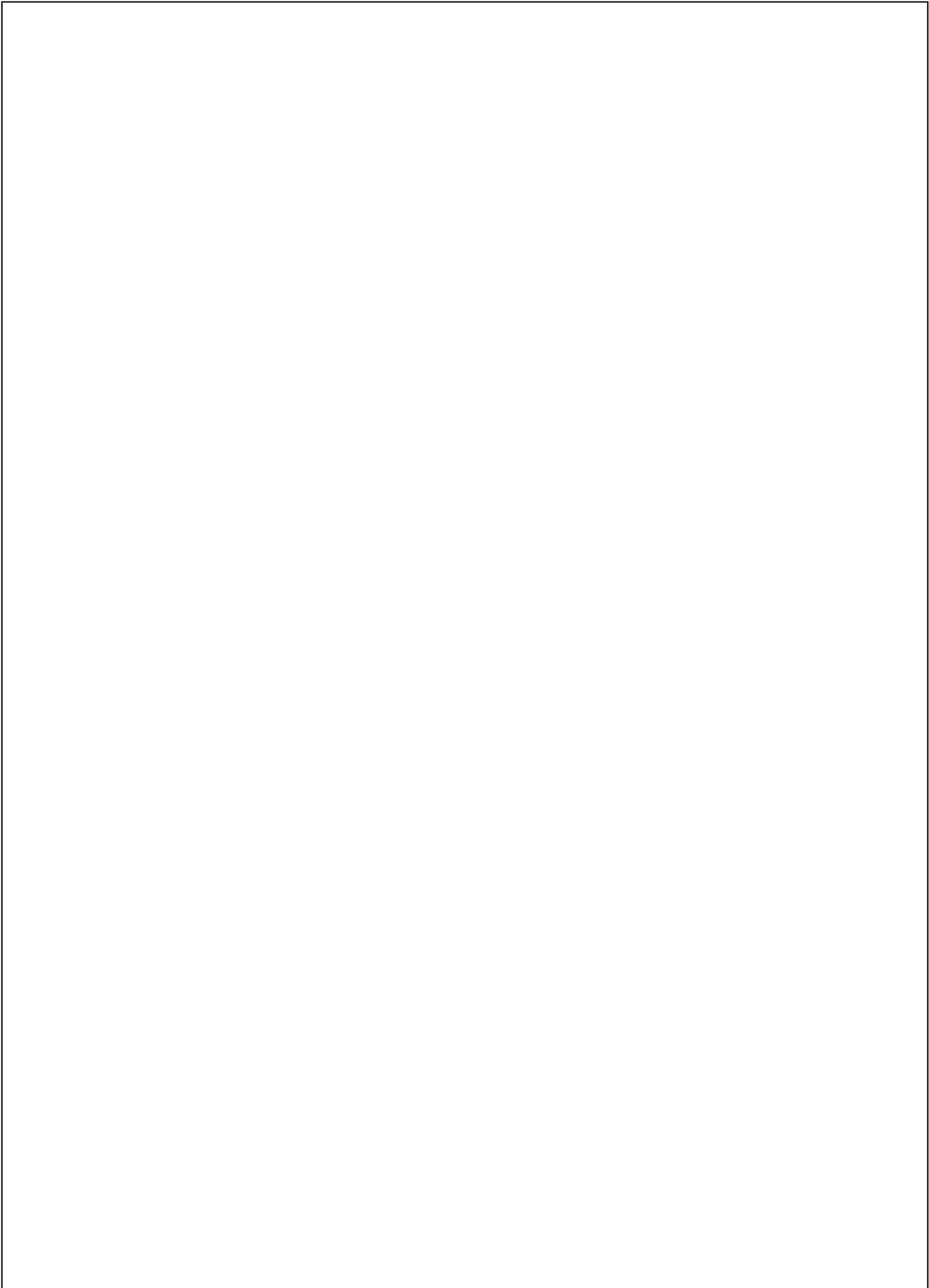
Overall comments

In this section, we'd like your views on the guidance overall, including:

- the clarity of the wording
- the accuracy of the content
- if there is anything missing
- if there is anything we should remove
- sections of the guidance we haven't asked a question about
- how easy it is to find the information you need.

When answering these questions, please bear in mind that our guidance isn't legal or clinical advice and applies to doctors in all four countries of the UK, in all areas of practice and specialties.

17 Overall comments



Putting the principles into practice

To show how the guidance might apply in a range of situations doctors ask us about, we plan to develop online resources such as case studies and interactive flowcharts (see our [website](#)* for existing materials).

For example, we know assessing capacity can be difficult, so we've developed a [mental capacity decision support tool](#)* to help doctors identify the steps to take if a patient's capacity is in doubt. We'd like to hear your ideas for other topics we could include in the tool, or other resources we could develop to help address this issue.

We know that there are some good examples of how to assess benefits and harms and explain these to patients, so would like to hear about any that we could share with the profession.

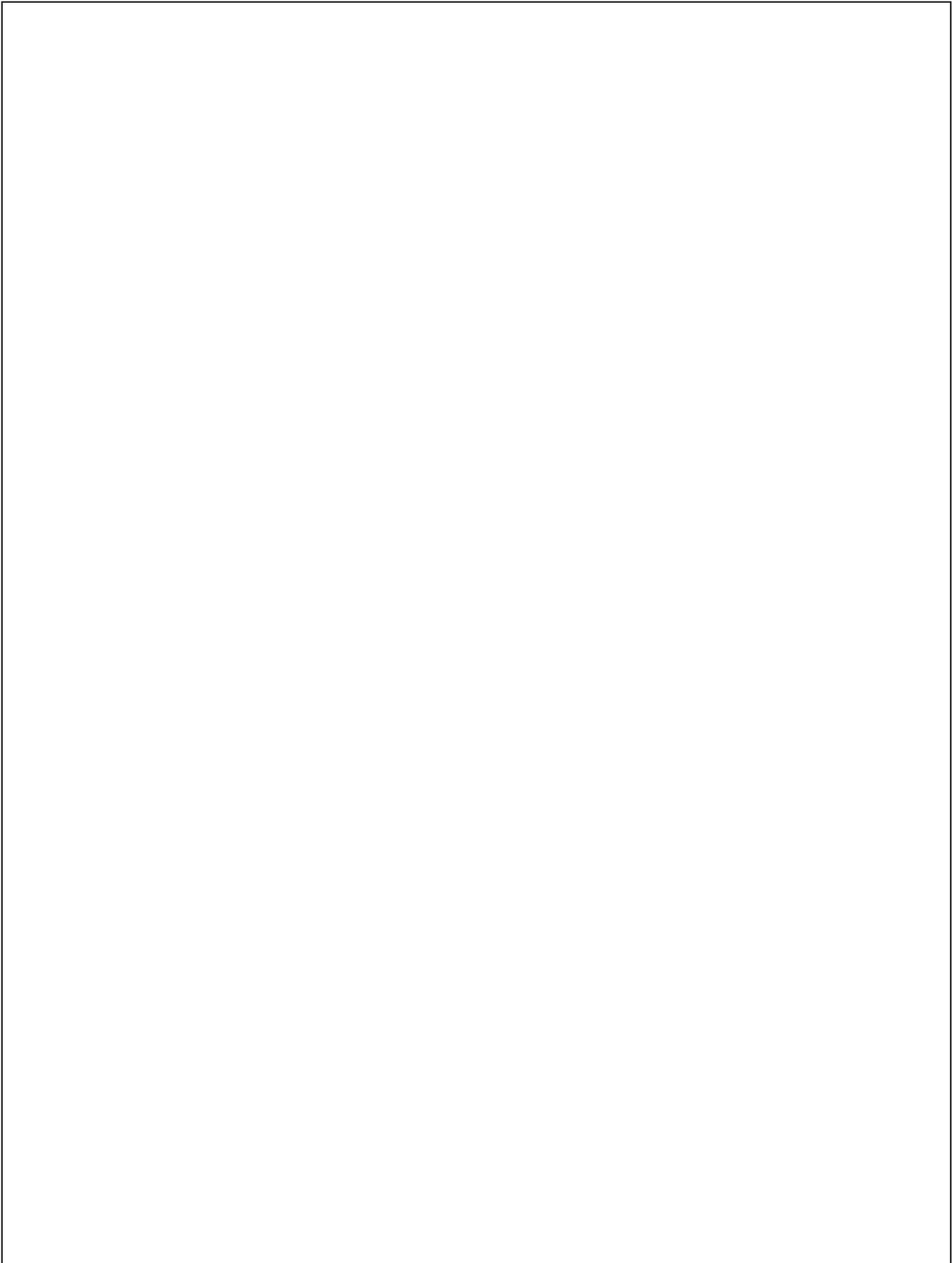
We're also planning to develop a patient resource, such as a discussion aid or leaflet, to accompany the guidance.

As well as developing online resources, we work closely with a wide range of organisations to embed the guidance in doctors' education, training and everyday practice. We'd like your suggestions on how to embed the guidance in practice and make sure it's followed. Specifically:

- topics around decision making and consent (for doctors or patients) we could cover and what format would be helpful
- how to put the principles into practice.

18 Comments

* <https://www.gmc-uk.org/ethical-guidance/learning-materials>



Equality and diversity

We'd like your views on the potential impact of this guidance on people who share protected characteristics under the *Equality Act 2010* (the protected characteristics are race, disability, age, sex, gender reassignment, sexual orientation, religion and belief, pregnancy and maternity and marriage and civil partnership).

19 E&D comments

The consultation process

We value feedback to help us continue to improve how we consult. Please answer these questions based on your thoughts of the questionnaire and how well we explained our proposals.

20 Was the consultation questionnaire clear?

Yes No Not sure

Comments

21 Was it easy to respond?

Yes No Not sure

Comments

22 How did you hear about this consultation? Please select all that apply.

- GMC website
- Another website
- GMC News ebulletin
- Other GMC newsletter/ebulletin
- Social media
- GMC event, workshop or meeting
- Non-GMC event
- Newspaper/radio
- Word of mouth
- Search engine
- Other (please say what)

About you

First name:
Last name:
Job title (if responding on behalf of an organisation):
Organisation name (if responding on behalf of an organisation):
Email address:

Would you like to receive updates about GMC/MPTS consultations you've participated in?

- Yes
- No

Are you responding as an individual or on behalf of an organisation?

- Individual (please continue to 'Responding as an individual')
- Organisation (please go to 'Responding on behalf of an organisation')

Responding as an individual

Which of these categories best describes you? Please only select one.

- Doctor (if you select this, please also answer the next question otherwise go to 'age')
- Medical student
- Medical educationalist (non-doctor)
- Other healthcare profession
- Patient
- Carer/Relative or Advocate
- Member of the public
- Lay GMC/MPTS Associate
- Other (please say what)

If you selected 'doctor' which of these categories best describes you? Please only select one

- GP
- Consultant
- Doctor in training
- Staff and Associate Grade
- Locum (GP)
- Locum (secondary care)
- Trainer/medical educationalist
- Responsible Officer/Medical Director

- Other leadership or management role
- Academic researcher
- Practising outside the UK
- GMC/MPTS Associate
- Retired
- Other clinical practice (eg prison health service)
- Other non-clinical practice. Please say what:

In this section we ask for information about your background. We use this information to help make sure we are consulting as widely as possible. Specifically, we use this information when we analyse responses to make sure we understand the impact of our proposals on [diverse groups](#).^{*} 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+
- Prefer not to say.

^{*}www.gmc-uk.org/about/how-we-work/equality-and-diversity

What is your gender?

- Female
- Male
- Prefer not to say
- I prefer to use my own term (please say what):

Do you have a disability?

- 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.

What is your ethnic group? (Please tick one)

White

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

Mixed or multiple ethnic groups

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

Asian or Asian British

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

Black, African, Caribbean or black British

Caribbean African

Any other black, African or Caribbean background, please specify_____

Other ethnic group

Arab

Any other ethnic group, please

specify_____

Prefer not to say

What is your religion?

No religion

Buddhist

Christian – Baptist

Christian – Brethren

Christian – Catholic

Christian – Church of England

Christian – Church of Ireland

Christian – Church of Scotland

Christian – Free Presbyterian

Christian – Methodist

Christian – Other

Christian – Presbyterian

Christian – Protestant

Christian – Pentecostal

Hindu

Jewish

Muslim

Sikh

Other (please say what)

Prefer not to say

Which of these options best describes your sexual orientation?

Bisexual

Heterosexual or straight

Gay man

Gay woman/lesbian

Other

Prefer not to say

What is your country of residence?

England

Northern Ireland

Scotland

Wales

Other (European Economic Area)

Other (rest of the world). Please say where

Responding on behalf of an organisation

Which of these categories best describes your organisation? Please select only one.

- Patient organisation
- Doctor organisation
- Independent Healthcare provider
- Medical school (undergraduate)
- NHS / HSC organisation
- Postgraduate body
- Regulatory body
- Public body
- UK government department
- Other (please say what)

In which country does your organisation operate? Please select only one.

England

Northern Ireland

Scotland

Wales

UK wide

Other (European Economic Area) (please say where)

Other (rest of the world) (please say where)

Thank you for responding to our consultation.

Email: gmc@gmc-uk.org

Website: www.gmc-uk.org

Telephone: **0161 923 6602**

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

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