



Decision making and consent

Supporting patient choices
about health and care

Draft guidance for consultation

About this guidance

Our core guidance for doctors, [*Good medical practice*](#),¹ says doctors must be satisfied that they have a patient's consent, or other valid authority, before carrying out any examination or investigation, providing treatment or involving patients or volunteers in teaching or research.

The purpose of this guidance is to help doctors to meet that standard. It focuses on doctors' legal and ethical duties to involve patients as much as possible in making decisions about their own health and care.

The guidance is addressed to doctors, and sets out the standards of good practice which we expect them to follow. There are resources to help doctors put this guidance into practice, available on our website at www.gmc-uk.org/ethical-guidance/learning-materials.

This guidance is also intended to be helpful to other health and care professionals and to patients.

Applying the principles

This is guidance on good practice. It sets out a framework that will help you to practise ethically and in line with the law. We expect you to follow the guidance but it is not a set of rules, and you will need to use your judgement about how to apply the principles to the particular situations you face in practice.

We indicate through the use of the terms 'must' and 'should' how much flexibility you have in following the guidance.

- 'You must' is used for an overriding duty or principle. This means that it is a legal requirement or a fundamental standard of ethical conduct applying to all doctors.
- 'You should' is used in two ways:
 - when we are explaining how to meet an overriding duty or principle. It acknowledges the need for flexibility in how doctors are able to meet the duty/principle in practice.
 - when we accept that the duty or principle will not apply in all situations or circumstances, or where there are factors outside a doctor's control that affect whether or how a doctor can follow the guidance.

Exercising judgement means different doctors may come to different conclusions when faced with the same situation. You should keep records that enable you to explain why you have chosen to proceed in the way you have. You must be prepared to explain and justify your decisions and actions.

¹ www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice

If you think you can't follow this guidance because of the systems, processes or environment in which you work, and that this risks compromising patient safety or dignity, you must follow the guidance in [*Raising and acting on concerns about patient safety \(2012\)*](#).²

If you don't have consent or other valid authority on which to carry out a particular intervention, you must not proceed with it.

Relationship between this guidance and action against a doctor's registration

Serious or persistent failure to follow this guidance that poses a risk to patient safety or public trust in doctors will put your registration at risk.

In dealing with a concern, it is not our role to punish or discipline doctors for past events. The purpose of any action we take is to protect the public by helping to make sure doctors on our register provide safe care and to uphold public confidence in doctors.

There is no automatic link between failure to follow this guidance and action against your registration. This is because the guidance sets out the principles of good practice, not thresholds for taking action to protect the public.

If we receive a complaint about a doctor, we consider it on the specific facts of the case, taking into account the factors relevant to the environment in which the doctor is working, and drawing on the advice of expert witnesses where necessary. We use our guidance as a

benchmark to assess whether a doctor's actions or decisions have fallen seriously or persistently below the standards we expect.

The scope of this guidance

The principles in this guidance are relevant to all the health and care decisions that you and your patient make together about mental and physical health. This includes, but is not limited to, decisions about treatments, procedures, investigations, examinations and referrals, and applies whatever the method of communication, including remote consultations.

When thinking about how to apply the principles in practice, you will need to take account of the specific situations in which you find yourself. We also produce supporting materials to show how the principles apply in different circumstances.

This guidance does not cover decisions about protecting or disclosing patient information (see [*Confidentiality: good practice in handling patient information*](#)) or making decisions about involvement in research (see [*Good practice in research*](#) and [*Consent to research*](#)). Though the principles are relevant to decision making with children and young people, specific, detailed guidance is covered in [*0–18 years: guidance for all doctors*](#).

² www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/raising-and-acting-on-concerns

Ethical and legal framework

Consent is integral to doctors' clinical interactions with patients. Patients have the right to make choices about their own lives. Doctors have an ethical and legal responsibility to involve patients as much as possible in making decisions about their own health and care. This should be a partnership based on openness, honesty, trust and good communication.

It's as important for doctors to understand what matters to patients – giving them the opportunity to share their needs, wishes and values, and listening to their priorities and concerns – as it is for the doctor to share information about the harms and benefits of the different options. The effectiveness of the latter depends to a considerable extent on the former.

Acting within the law

Doctors must act within the law and apply professional standards to their practice. Although we don't expect doctors to be legal experts, you should be familiar with laws relevant to your practice and know when to get expert legal advice.

The laws governing decision making with patients vary across the UK. This guidance is not legal advice but it takes account of, and is consistent with, current law across the UK and supports doctors to act within the law.

The guidance avoids using legal terminology specific to one country. Instead we use a broader term which conveys the same meaning. Importantly, the guidance uses 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 for themselves. This involves weighing up the risks of harm, benefits and burdens for the individual patient. It is consistent with the legal requirements to consider whether treatment 'benefits' a patient (Scotland), or is in the patient's 'best interests' (England, Wales and Northern Ireland), and to apply the other legal principles used to determine capacity across the UK.

In the legal annex to this guidance, we summarise some of the key elements of relevant law, including the requirements of the common law as well as the mental health and mental capacity legislation across the UK. In the main body of the guidance, we give advice on how to apply ethical and legal principles in practice. We only refer to the law of one specific jurisdiction where it is necessary to do so.

The footnotes, references and legal annex give background information. References to publications by other organisations are examples of available national resources.

If you're not sure how the law may apply in a particular situation, you should get advice from senior colleagues or others within your organisation, consult your medical defence organisation or professional association, or get independent legal advice.

The main principles of this guidance

Support patient decision making. Help patients make choices and decisions about their own health and care. Give them the information that is relevant to them, in a way they understand. Think about whether there is anything you can do to make it easier for them to consider the options and come to a decision.

Listen to your patient and those close to them. The information your patient and those close to them share with you is as important as what you tell them. Take the time to ask questions to understand what matters to them.

Share information that is relevant to your patient. Treat your patient as an individual and give them the information they need to make a decision. Think about what matters to them and the impact that different options might have. Tailor the information you share with them to reflect their particular concerns, wishes and values.

Understand the different roles you and your patients play in decision making. Use your knowledge and expertise to advise your patients, but do not put pressure on them to make a particular decision.

Respect your patients' decisions. Where your patient is able to make decisions about their treatment and care, respect and value their right to do this in consultation with other people of their choosing, even if you disagree with their

decision or do not understand it. But if a patient requests a treatment that you believe would not be beneficial to them overall, you do not have to provide it.

Recognise the importance of the decision-making process. Although it is important to accurately record discussions and decisions, the way in which the patient gives their consent is less important than the quality of the decision-making process that you and your patient have followed.

Presume, assess, maximise and review capacity. Start from the position that every adult patient can make their own decisions and take all reasonable steps to help patients do this. Recognise that capacity can fluctuate and is specific to each choice or decision. Assess, maximise and review your patient's capacity to make each separate decision.

Involve your patient as much as possible in discussions and decisions about their care, even where they cannot make a decision. Give weight to their values, wishes and preferences even though it may not always be appropriate to do as they ask.

Involve others when making decisions where patients are unable to do so. Work with those close to the patient, other healthcare professionals or people who have a legal role in advocating for or making decisions on behalf of the patient to identify and choose between the options that may be of overall benefit to the patient.

How decisions are made

Decision-making frameworks

- 1 Doctors should work in partnership with patients and support them to take as active a role as possible in decision making. Part One of this guidance sets out how you should do this.
- 2 When providing care to patients, the way in which you work with them to choose the most appropriate option, and your authority to provide this, rests on one of three decision-making frameworks. Part Two sets out the practical steps you need to take to follow the appropriate decision-making framework:
 - a Where a patient is able to make a decision and give or withhold their consent. In most cases, patients make decisions after considering the advice and information they have been given. They choose between the different options and if they decide to go ahead with an intervention, they express their consent to the doctor or a member of the care team.
 - b Where a patient lacks the capacity to give or withhold their consent. Sometimes a patient may be unable to give or withhold their consent, because they lack the capacity to do so. In these circumstances it is necessary to decide what will be of overall benefit to the patient and what is the most appropriate way in which to proceed.

These decisions occur within a legal framework, and these frameworks differ across the four countries of the UK. You will usually make decisions in consultation with the wider healthcare team, those close to the patient, and anyone who is legally authorised to act on the patient's behalf. If there are disagreements that can't be resolved then decisions may ultimately need to be made by the courts.

- c Where you have legal authority to make a decision to protect the patient or others. In some very specific and limited circumstances, such as when assessing or treating a patient under particular mental health legislation, you may have to make a decision to protect the patient or the public – even where that patient has the legal capacity to make the decision. These decisions are also governed by law, which differs across the UK.

Responsibility and delegation

- 3 If you are the doctor who will carry out the proposed intervention, you must make sure the decision about whether to undertake the intervention has been made appropriately, following the relevant framework. You must discuss the options with the patient and any other relevant people or delegate appropriately.
- 4 We recognise that discussions and decisions about health and care take place at different levels, including at team level. If it's not practical for you to have these discussions and you consider it appropriate in the circumstances, then unless you are carrying out a cosmetic intervention, you

can delegate the responsibility to someone else.³ By delegate, we mean pass the responsibility to a colleague – for example to another colleague in your team or in another specialty, or to another healthcare professional.

- 5 If you delegate, you must make sure the person you delegate to:
 - a is suitably trained and qualified
 - b has sufficient knowledge of the proposed intervention, and understands the risks involved and the potential benefits
 - c is sufficiently informed of the patient's needs
 - d understands and agrees that they will revert to you for further advice or information if necessary.
- 6 When deciding whether it is appropriate to delegate, you should consider:
 - a the nature of the intervention, including its seriousness and complexity
 - b the level of uncertainty surrounding the outcome
 - c your existing relationship with the patient and any relationship your patient has with the person to whom you are considering delegating
 - d any concerns that you anticipate the patient may have.
- 7 If you delegate, you must be satisfied that the patient and anyone else who is involved in the decision has been given enough time and information to make a decision or, where they are unable to make a decision, to express their views. Where

the patient is able to make a decision, you must make sure they have decided to go ahead and have given their consent before you begin any intervention. If the person to whom you have delegated raises concerns about their competence to carry out your request, you should offer support or make alternative arrangements

- 8 If a colleague asks you to have discussions and seek a patient's consent on their behalf, you must make sure you have sufficient knowledge and expertise to do this. If you do not, you should explain this to the other doctor and seek support. If you feel you are being placed in a position where you are insufficiently supported you should raise concerns, following the guidance in *Raising and acting on concerns about patient safety*.

3 If you're carrying out a cosmetic intervention, you must follow the advice in *Guidance for doctors who offer cosmetic interventions*.

Part 1:

Supporting patient decision making

- 9 When making decisions about health and care it is important to give weight to the patient's wishes and knowledge of their own condition as well as your expertise and clinical knowledge.
- 10 You must take all reasonable and proportionate steps to support patients to make their own decisions wherever possible. Where that isn't possible, either because they lack capacity to make the decision (see paragraphs 76–101), or because you need to make a decision about their treatment and care under specific legislation to protect the patient or the public (see paragraphs 104–107), you must support their involvement in decision making as far as you can. This section explains how you should do this.

Doctors and patients sharing information

- 11 For a relationship between doctor and patient to be effective, it should be a partnership based on openness, honesty, trust and good communication. You must listen to patients' concerns, ask for and respect their views and values, and encourage them to ask questions. You should not make assumptions about the information they might want or the factors they might consider significant.
- 12 You must give patients the information they want or need to make a decision in a way they can understand. You should consider whether a patient might need more time with you or the healthcare team, or could benefit from getting information before a consultation, to make sure their needs can be met.
- 13 You should tailor your approach to discussions with patients according to:
 - a their needs, wishes, values and priorities
 - b their level of knowledge about, and understanding of, their condition, prognosis and the possible options
 - c the nature, complexity, urgency and level of risk associated with the proposed options .
- 14 Where the patient would like another person such as a relative, partner, friend, carer, or advocate to be involved in discussions or help them make decisions, you should accommodate their wishes where possible. If they can't make a decision themselves, you should give them the information they want or need to express their views about the decision.

- 15** You must give balanced information to patients about their options, including the option of doing nothing. If you recommend a course of action, you should explain your reasons for doing so. You should be aware of how your own wishes or preferences might influence the advice you give and you must not put pressure on a patient to accept your advice.
- 16** You must explain clearly the scope of any decisions to be made. This will apply particularly if:
- a** the intervention is to be provided in stages, with the possibility that changes or adjustments might be needed
 - b** different doctors or healthcare professionals will provide particular parts of an investigation or treatment, such as anaesthesia and surgery
 - c** a number of different interventions are involved
 - d** uncertainty about the diagnosis or the options might only be resolved when the intervention has begun, when the patient might be unable to make decisions.⁴

In such cases you should discuss and agree with patients how decisions will be made at later stages.

- 17** You must check whether patients have understood the information they have been given, and if they would like more information before they make a decision.

- 18** You should not hold back information the patient needs to make a decision about the available options for other reasons, including when a relative, partner, friend or carer asks you to. But you should consider carefully the time and manner in which you share information.⁵
- 19** If you don't share all the information at the same time, you must record your reason for doing so. You must be prepared to explain and justify your decision. You should consider when to share the information so it can be used to make a decision.

Maximising your patient's ability to make a decision

- 20** To make choices and decisions, patients must be able to understand and retain the relevant information and use it to make a decision. This means they need clear, accurate information about the harms and benefits of any proposed course of action. This needs to be presented in a way they can understand and is meaningful to them in their individual circumstances, so they can use it to consider the options and come to a decision.
- 21** Some patients may be able to make simple decisions, but may have difficulty if the decision is complex or involves a number of options. Other patients may be able to make decisions at certain times but not others, for reasons that might include:

⁴ Note for pathologists and radiologists: there may be times when uncertainty about a diagnosis can only be resolved by investigations that were not specifically ordered as part of the original request for testing. If these investigations appear to fall outside of the scope of the patient's consent, or there are particular sensitivities around the condition for which you wish to test, you must contact the treating doctor to establish whether further discussion with the patient is necessary before proceeding.

⁵ In very exceptional circumstances you may feel that sharing information with a patient would cause them serious harm and in such circumstances it may be appropriate to withhold this information. Please see the legal annex for relevant case law. [The legal annex will be drafted post-consultation. Please see *Montgomery vs Lanarkshire 2015*].

- a the nature and severity of their condition
 - b fluctuations in their conditions
 - c the difficulty, complexity, seriousness or urgency of the decision
 - d whether the format or manner of communication meets their needs
 - e the time or place of the discussion
 - f your communication skills and the way you interact with the patient
 - g whether they are in any pain or affected by medication
 - h the time you give them to ask questions or consider the information
 - i the support they have available.
- 22** You must take all reasonable steps to plan for foreseeable changes in a patient's capacity to make a decision and help patients to make decisions at a time when they are able to do so.
- 23** When discussing a decision you should:
- a check whether the patient needs any more support to understand, retain and evaluate information or to communicate their wishes. For example, patients may find it helpful to bring someone with them to consultations or they may need written or audio information. Wherever practical, you should make arrangements to give them the support they need
 - b take account of patients' individual approaches to making decisions, for example by giving them the opportunity to discuss the options with people of their choosing
 - c if you support your discussions with patients by using written material, or visual or other aids, make sure the material is accurate, up to date and relevant to the individual patient
- d wherever possible, share information in a place and at a time when you think the patient is most likely to be able to understand and retain it
 - e give information that the patient may find distressing in a considerate way and allow them an appropriate time to digest the information before asking them to make a decision. Use your knowledge of your patient and what matters to them to help anticipate what they might find distressing and to do what you can to minimise their distress
 - f where appropriate, involve other members of the healthcare team in discussions with the patient
 - g give the patient time to reflect, before and after they make a decision, especially if the information is complex or what you are proposing involves significant risks
 - h make sure the patient knows if there is a time limit on making their decision, and who they can contact in the healthcare team if they have any questions or concerns.
- 24** If a patient is likely to have difficulty retaining information, you should offer them a record of your discussions, detailing what decisions were made and why. For example, you could give them a written record, or you could suggest the patient makes an audio recording of the discussion.

Assessing and explaining benefits and harms

- 25** To have effective discussions with patients you must make sure you are aware of the known potential benefits and the risks of

harm that may result from the proposed options. This includes the potential outcome of taking no action.

26 If the proposed course of action carries with it a known risk of harm that you believe the patient would consider to be serious in their circumstances, you must tell the patient even if you think it is very unlikely to occur. You should also tell patients about less serious side effects or complications if they occur frequently, or if you think the patient may attach particular significance to them, and explain what the patient should do if they experience any of them.

27 You must use clear and consistent language when discussing risks of harm and potential benefits with patients and you should be aware that patients may understand information about risk differently from you. If they will help the patient to understand, you should use clear and accurate written information or visual or other aids to explain risk. For example, when explaining the likelihood of a particular outcome, you may find it helpful to use infographics or to illustrate probability using populations that have meaning for the patient.

28 You should check that your patient understands the terms you use, particularly when describing the seriousness, frequency and likelihood of a possible harm. You should invite questions and discussion about the information you share.

29 If a patient does not want to know about the possible harms of a proposed course of action, or asks you or someone else to make a decision on their behalf, you must follow the guidance in paragraphs 33–35.

30 You must keep up to date with developments in your area of practice, which may affect your knowledge and understanding of the risks of harm associated with the investigations or treatments you provide. You must make sure the information you give to patients is accurate and up to date.

Answering questions and dealing with uncertainty

31 You must answer patients' questions honestly and accurately, and as fully as is practical in the circumstances. If you can't answer a question, you should consider whether you can find out the answer by consulting another person or resource, or whether there is an inherent uncertainty. If you can find out the information, you should do so and answer the patient's question.

32 Where the evidence of the benefits, harms and burdens of a particular option is unclear or there is uncertainty about the clinical effect of a particular intervention on an individual patient, you should explain this to the patient.

When patients do not want to be involved

33 Sometimes patients may want someone else to make a decision for them. Or they may want to make the decision, but don't want any information about the options.

34 If a patient who has capacity asks you to make decisions on their behalf or wants to leave decisions to a relative, partner, friend, carer or another person close to

them, you should try to find out why and explore whether you can take any actions that might reassure and support them. You should explain why it's important that you and the healthcare team are confident that the patient has made an informed decision about how to proceed.

- 35** If, after discussion, a patient insists that they don't want even this basic information, you must explain the potential consequences of them not having it. This might include being unable to proceed if you are not confident that their consent would be valid, or if you are not confident that the proposed course of action would be beneficial to the patient overall. You must record the fact that the patient has declined this information. You must also make it clear that they can change their mind and have more information at any time.

Time and resource constraints

- 36** Because of pressures on your time or the limited resources, it can be difficult to give patients as much information or support to make a decision as you, or they, would like. To help, you should consider the role other members of the health and care team might play, for example in gathering and giving information and answering questions before or after your contact with the patient. You should also consider what other sources of information and support are available to the patient (and any family or carer supporting the patient). For example, patient information leaflets, advocacy services, expert patient programmes, or support groups for people with specific conditions.

- 37** You should do your best to make sure patients with additional needs, such as those with disabilities, have the time, support and any reasonable adjustments they need to make a decision. In all cases, you must treat patients fairly and not discriminate against them.

- 38** If factors outside of your control mean that you can't give patients the time or information they need and this seriously compromises their ability to make an informed decision, you should raise your concerns with your employer or contracting organisation. See our guidance on *Raising and acting on concerns about patient safety* and our decision support tool. If you don't have consent or other valid authority to carry out a particular intervention, you must not proceed with it.

Part 2: Making a decision

Where your patient is able to make the decision and give consent

- 39** Where an adult patient has capacity, and unless they are subject to specific legislation that restricts their ability to make decisions (see paragraphs 104–107), they have the right to make their own decisions about their care, and they can do so in consultation with people of their choosing.

- 40** You must respect your patient's decision to refuse a particular course of action, even if you disagree with it or don't understand it. It may be reasonable to ask more questions and offer more support to a patient where, for example, their decision seems out of character or inconsistent with their beliefs and values, or they don't appear to understand the consequences. But you must not assume a patient lacks capacity simply because they make a decision that you disagree with or do not understand.
- 41** If you are concerned that a patient is making a decision that you consider unwise for them, you should explain your concerns clearly and outline the possible consequences of their decision. But you should not let your own wishes or preferences influence the advice you give and you must not put pressure on a patient to accept your advice.
- 42** If a patient asks for treatment or care that you don't think would be beneficial to them, you should explore the patient's reasons for requesting it. When assessing any likely benefit, you should take into account factors that are significant to the patient, including non-clinical factors such as the patient's beliefs or views and the possible effect on their lifestyle. If after further discussion you still consider that it would not be of benefit to the patient, you do not have to provide the treatment or care. But you should explain your reasons to the patient and explain any other options that might be available, including the option to seek a second opinion.
- 43** You must not exceed the scope of the authority given by a patient, except in an emergency. If an emergency arises you must follow the guidance in paragraphs 89 and 90.
- 44** If you are concerned that a patient can't make a free decision because they are under undue influence or external pressure, you should follow the guidance in paragraphs 60–64.

Expressions of consent

- 45** Once a patient has made their decision, they may express their consent to you for a particular course of action.
- 46** Before accepting a patient's consent, you must consider whether they have been given the information they want or need, in a way they can understand. And you must consider how well they understand the details and implications of what is proposed. This is more important than how their consent is expressed or recorded.
- 47** Patients can express their consent in many different ways. This may be explicit, through written, spoken or signed language. Or it may be expressed through non-verbal communication, such as opening their mouth to allow you to examine their throat, or tilting their head so you can examine their ear.
- 48** You should take a proportionate approach to the way in which consent may be expressed. You should take into account the nature of the intervention and its urgency, the level of risk and the complexity of the decision, as well as any relevant factors related to the individual patient, such as their level of understanding or communication preferences.
- 49** Written consent is often emphasised and may sometimes be legally required. But regardless of how the patient expresses

their consent, you must make sure they have received all the relevant information in a way they understand and have had appropriate time to make a decision.

- 50** You are legally required to obtain written consent for certain treatments, such as fertility treatment. You must follow the laws and codes of practice that govern these situations.

Recording discussions

- 51** You must record the key elements of discussions about options, harms and benefits you have had with the patient, those close to them, anyone who has a legal role in the process and other members of the healthcare team.
- 52** You should take a proportionate approach to the level of detail you record. But you should usually include:
- a summary of the information you discussed
 - any specific concerns or requests expressed during discussions
 - any written, visual or audio information given to the patient, those close to them or those with a legal role in the process
 - details of any decisions made.

Planning future care

- 53** There are many situations in which thinking about care options in advance can be helpful. This gives patients the chance to think about the options before they need to make a decision or take an action. For example, in maternity care, patients often make birth plans in advance; in psychiatric care, patients with bipolar disorder may make plans for their care should they experience future episodes of mania; and patients who frequently present at

emergency departments may find it helpful to discuss what they would like to happen if they attend again.

- 54** You should consider making plans in advance where:
- a** the patient may find it difficult to make decisions at a later stage, either because loss or impairment of capacity or insight is a foreseeable possibility or for other reasons
 - b** action does not need to be taken immediately, but where decisions may need to be made quickly at a later stage
 - c** the patient has a condition that will affect the length or quality of their life.⁶
- 55** When making plans for treatment and care in advance, you should encourage your patient to think about what they might want in the event of different outcomes or developments, and to discuss their wishes and concerns with you and the healthcare team.
- 56** Such discussions might cover:
- a** the patient's wishes, preferences or fears in relation to their future care, including any treatments, investigations or examinations they would want to refuse, and under what circumstances
 - b** any interventions that might become necessary in an emergency, such as admission to hospital or transfer to another unit, an emergency caesarean section or treatment for an acute infection
 - c** the feelings, beliefs or values that may be influencing the patient's preferences and decisions.

⁶ If you are giving treatment or care to a patient who is reaching the end of their life, you must follow the guidance in Treatment and care towards the end of life: decision making.

57 A patient may want to nominate someone to make decisions on their behalf if they lose capacity, or refuse a particular treatment in advance. In these cases, you should explain that there may be ways to formalise their wishes and explain how they can seek support or get independent advice about this.

58 You must record the discussion and any views or decisions the patient expresses. You should make sure a record of the plan is made available to the patient and others involved in their care, so everyone is clear about what has been agreed. This is particularly important if the patient has made an advance decision to refuse treatment.⁷ You should bear in mind that care plans need to be reviewed and updated as the situation or the patient's views change.

59 You should record any decisions made, wherever possible while the patient has capacity to understand and review them. You must bear in mind that advance refusals of treatment may need to be recorded, signed and witnessed.

60 If you are giving treatment or care to a patient who is reaching the end of their life, you must follow the guidance in Treatment and care towards the end of life: decision making.⁸

If you are concerned a patient may not be able to make a decision freely

61 There are many factors a patient may take into account when they make a decision. But it's important that none of these factors influence a patient to such an extent that they are no longer able to exercise their free will. If a patient can't make their decision freely, their consent to a particular course of action will not be valid.

62 Patients may be put under pressure from others to accept a particular intervention. This pressure may come from individuals, such as partners, relatives or carers; organisations, such as employers or insurers; or large scale systems, such as the criminal justice or benefits system.

63 You should be aware of this possibility and of other situations in which patients may be particularly vulnerable or susceptible to pressure. Such situations may include, for example, if they are: experiencing domestic or other forms of abuse, resident in a care home, cared for or supported by others because of a disability, detained by the police or immigration services, or in prison. Patients who are subject to compulsory treatment or assessment under mental health legislation, or who are at risk of becoming so, may also be under pressure to agree to a particular course of action outside of any treatment or investigation they may be legally compelled to follow.

64 In some cases external pressure on patients to agree to a particular course of action may be considerable. You should do your best to make sure patients have considered the available options and the possible

⁷ Please see the legal annex for more information about advance refusals. [The legal annex will be drafted post-consultation. Please see Mental Capacity Act 2005 ss 24-26 for information about advance decisions in England and Wales. In Scotland, advance decisions have not been tested by the courts, but it is likely that they would be treated as legally binding if they were directly applicable to the circumstances. In Northern Ireland, they are governed by common law although when it comes into force, the Mental Capacity Act (Northern Ireland) (2016) will place them on a statutory footing.]

⁸ www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

consequences of these, and have reached their own decision. You should follow the steps in paragraph 23 and any other steps you think may help them to make a decision. This might include, for example, giving them more time and a safe, quiet space to consider the options, making sure you have an opportunity to talk to them on their own, or signposting them to suitable specialist support services. You must make sure your patient is aware that they can refuse to proceed if they want to. You don't need to proceed with an intervention if you do not think it will be beneficial to the patient.

- 65** If, after doing this, you believe a patient is under such extreme pressure to agree to or refuse a particular intervention that they are no longer able to freely exercise their will, or that their capacity to make a decision may be impaired,⁹ you should get legal advice. Paragraphs 76–101 give advice on what to do if your patient may lack capacity to make a decision.

Where your patient may lack the capacity to make the decision

- 66** Mental capacity is the ability to make a decision. To do this, patients must be able to do all of the following:
- a** understand any information relevant to the decision in question
 - b** retain that information
 - c** use or weigh that information to make their decision¹⁰

⁹ Where adults lack capacity due to fear, coercion or undue influence, in England and Wales, the High Court can authorise acts intended to protect them and enhance their welfare. Please see the case law section of the legal annex. [The legal annex will be drafted post-consultation. Please see Re DL [2012] EWCA Civ 253]

¹⁰ *The Mental Capacity Act (Northern Ireland) 2016*, which is not yet in force, includes an additional requirement; the patient must appreciate the relevance of the information to the decision in question and must use and weigh that information to reach a decision. When this legislation comes into force, doctors practising in Northern Ireland will need to take account of this.

- d** communicate this decision.

- 67** If a patient does not have the capacity to make the decision in question, they are legally unable to give their consent to the proposed intervention.
- 68** There will be times when you think that your patient may not have the capacity to make a decision. Remember that this is a complex area and although there is legislation and there are statutory codes of practice to help you, determining capacity is a matter of judgement. You can find links to the codes of practice in the *Other sources of information and guidance*¹¹ section at the end of this document.
- 69** The guidance that follows is consistent with the law across the UK. You must keep up to date with, and comply with, the laws and codes of practice that apply where you work. There is some information about the law on capacity in the legal annex. If you're not sure how the law applies in a particular situation, you should consult your defence body or professional association, get advice through local procedures or seek independent legal advice.

Presumption of capacity

- 70** You must begin with the presumption that every adult patient has the capacity to make decisions about their care, and to decide whether to agree to, or refuse, an examination, investigation, treatment or other intervention. You must only regard a patient as lacking capacity once it is clear that, having been given all appropriate help and support (as outlined in part 1), they are unable to do everything listed in paragraph 76.

- 71** You must not assume a patient lacks

¹¹ We will update this during the review and publish alongside the final guidance.

capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including mental illness), views, beliefs, apparent difficulties in communicating, or because they make a decision you disagree with or do not understand.

Assessing capacity

- 72** When making a decision with a patient, it is your responsibility to assess whether a patient has the capacity to make the decision in question.
- 73** In some cases, it may be clear that the patient does not have capacity and it may not be practically possible to take any steps to maximise their capacity. For example, if a patient is unconscious and treatment has to begin quickly. In other cases there may be a considerable amount you can do to help support your patient's involvement in the decision-making process, following the steps in Part 1. Your discussions with your patient throughout will help to inform your assessment of their capacity. But you must not make a final judgement about their capacity to make a particular decision until the time the decision needs to be made, and only once the patient has had all appropriate help and support.
- 74** Capacity is decision specific and can fluctuate. You must not assume that because a patient lacks capacity to make a decision on a particular occasion, they lack capacity to make any decisions at all, or will not be able to make similar decisions in the future.
- 75** You must take account of the advice on assessing capacity in any statutory or other relevant guidance that applies. You can

find links to the codes of practice in the *Other sources of information and guidance* section at the end of this document.

- 76** If, after making your assessment, you remain in doubt about the patient's capacity to make the decision, you should¹² seek (further) advice from:
- a** nursing staff or others involved in the patient's care, or those close to the patient, who may be aware of the patient's usual ability to make and communicate decisions
 - b** colleagues with relevant specialist experience, such as psychiatrists, neurologists, speech and language therapists or liaison nurses.
- 77** If you are still unsure about the patient's capacity to make a decision, you must follow any relevant local or statutory procedures for resolving this. If this is not successful, then you must get legal advice with a view to asking a court to determine capacity.
- 78** Where a patient can't make a decision for themselves because they lack capacity, a decision must be made about which options may be of overall benefit to the patient and which option would be least restrictive of the patient's future choices.

Assessing the overall benefit of different options

- 79** Where a patient can't make a decision for themselves because they lack capacity, you must identify which options may be of overall benefit to the patient and

¹² If you are practising in Northern Ireland, you *must* seek this further advice.

decide between them, considering how closely they align with the patient's wishes and values, and to what extent they may be restrictive of the patient's rights and freedoms, including their future choices.

- 80** If you are responsible for making the decision about overall benefit, those close to the patient and members of the health and care teams are likely to have knowledge about the patient's wishes, values and preferences and any other personal factors that you should take into account. You may also find information about the patient's wishes in their notes, advance care plan or other record, such as an advance request for or refusal of treatment.
- 81** To reach a view about the overall benefit of a particular option, you must weigh its benefits against the burdens and risks of harm, for that particular patient.
- 82** The benefits, burdens and harms associated with an intervention are not limited to clinical considerations. You should be careful to take account of the other factors relevant to the circumstances of each patient, thinking about the likely short term and longer term outcomes.
- 83** If a patient who lacks capacity has a legal proxy with authority to make decisions on their behalf, their legal proxy will make these judgements with advice from you and others involved in the patient's care. There is more information about legal proxies in the legal annex.
- 84** In making decisions about the treatment and care of a patient who lacks capacity, you must:
- a** make the care of your patient your first concern
 - b** treat your patient as an individual and respect their dignity
 - c** support and encourage your patient to be involved, as far as they want to and are able, in decisions about their treatment and care
 - d** treat your patient with respect and not discriminate against them.
- 85** You must also consider:
- a** whether the patient's lack of capacity is likely to be temporary or permanent
 - b** which options for treatment would provide overall benefit for the patient
 - c** which option, including the option not to treat, would be least restrictive of the patient's future choices
 - d** the seriousness of any proposed intervention, and any serious consequences that might result from it
 - e** any evidence of the patient's preferences, expressed at a time when they had capacity to make the decision in question, such as an advance statement or decision
 - f** 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
 - g** any need to appoint a representative or advocate
 - h** the views of people close to the patient, such as family members, friends and carers on the patient's preferences, feelings, beliefs and values, and whether they consider the proposed treatment to be in the patient's best interests
 - i** the patient's preferences now, if they are able to express them
 - j** anything else you and others in the health and care teams may know about the patient's wishes, feelings, beliefs and

values and any other factors the patient would be likely to consider if they were able to.

Resolving disagreements

- 86** You should aim to reach a consensus about a patient's treatment and care, allowing enough time for discussions with those who have an interest in the patient's welfare.
- 87** Sometimes disagreements may arise between members of the healthcare team, those close to the patient and the patient themselves. These disagreements may be about whether the patient has capacity. Alternatively, there may be agreement that the patient lacks capacity, but disagreement about what to do.
- 88** It is preferable and usually possible to resolve disagreements through local processes. For example, by involving an independent advocate or local mediation service, consulting a more experienced colleague, holding a case conference or seeking advice from a clinical ethics committee. You must follow any formal steps to resolve disagreement that are required by law or set out in a relevant code of practice. You must make sure you are aware of the different people you must consult, their different decision-making roles and the weight you must attach to their views. There is more information about this in the legal annex.
- 89** If, having taken these steps, there is still significant disagreement, you should get legal advice on applying to the appropriate court or statutory body for review or for an independent ruling. Your patient, anyone appointed to act for them, and those close to the patient, should be informed as early

as possible of any decision to start legal proceedings, so they have the opportunity to participate or be represented.

The scope of treatment in emergencies

- 90** The presumption of capacity applies even in emergency situations. But you may find that the steps you can take to maximise a patient's capacity in an emergency situation are more limited than at other times. And in some circumstances it may be immediately clear that the patient does not have capacity (see paragraph 72). If a patient does not have capacity, their treatment in an emergency situation should be provided according to what is in their overall benefit.
- 91** The treatment you provide should be the least restrictive of the patient's rights and freedoms, including their future choices. For as long as the patient lacks capacity, you should provide ongoing care on the basis of the guidance in paragraphs 80–100. If the patient regains capacity while in your care, you must tell them what has been done, and why, as soon as they are sufficiently recovered to understand. And you must discuss with them the options for any ongoing treatment.

Where you have legal authority to make a decision to protect the patient or other people

- 92** In some circumstances, which are set out in law, it may be necessary to restrain or restrict a patient's movements or carry out an intervention without the patient's

consent to protect the patient or the public from harm, even where that patient meets the legal test of capacity to make the decision, or to enable treatment to be provided to the patient in a particular place.¹³

- 93** The circumstances in which you can restrain or restrict the movement of an adult patient and provide treatment without consent are necessarily subject to strict safeguards, because such actions interfere with an individual's right to make decisions about their own health and care.
- 94** If you consider it necessary to use these legal powers to treat or assess a patient without consent, you must follow the procedures set out in the relevant law and statutory guidance that applies in the country where you practise. The legal annex gives some information about the law in this area. If you're not sure how this applies, you should get advice from your defence body, professional organisation or an independent legal advisor.
- 95** Where a patient is assessed or treated in these circumstances, it's important to remember that you should still support and encourage their involvement in decisions about their care. For example, a patient may not be able to choose whether to receive treatment, but you may be able to take account of their preference for a particular treatment option or delivery method in deciding how to manage their care.

Recording decisions

- 96** You must record any decisions made and the reasons for them. Where the patient has capacity and has given their consent, it may be appropriate to record the discussions and their decisions on a separate consent form if these are in use in your organisation.
- 97** You must also record any discussions you've had that have informed the decision, following the advice in paragraphs 62 and 63. This should include any relevant information about the circumstances in which the decision was made, where this might be helpful to subsequent decisions about the patient's care.

Reviewing decisions

- 98** Before beginning any intervention, you or a member of the healthcare team should check that it is still appropriate to do so. You must respond to any new or repeated concerns or questions raised by the patient or others involved in the decision.
- 99** Patients can change their mind at any time, and if the patient has capacity to consent to the intervention, you should check that they still want to go ahead before you proceed. If the patient lacks this capacity, but there is a person who has formal legal authority to make a decision on their behalf, you should check with that person that they are still happy to go ahead.
- 100** It is particularly important to do this if:
- a** you have not personally had a discussion with the patient, for example because the patient was initially seen by a colleague
 - b** significant time has passed since the initial decision was made

¹³ Please see the legal annex for further information. [The legal annex will be drafted post-consultation. Please see the Mental Health Act 1983, as amended by the Mental Health Act 2007; Nottinghamshire Healthcare NHS Trust v RC [2014] EW COP 1317; the Public Health (Control of Disease) Act 1984; the Public Health etc. (Scotland) Act 2008; the Public Health Act (Northern Ireland) 1967]

- c there have been changes in the patient's condition, or in any aspect of the proposed investigation or treatment
- d new information has become available, for example about the risks of treatment or about other treatment options
- e you have any reason to believe the patient has changed their mind or appears unhappy to go ahead
- f you have any reason to believe that the patient's ability to make a free decision may have been inhibited. In such circumstances you must follow the guidance in paragraphs 70–74.

101 You must make sure patients and others involved in decision making are kept informed about the progress of their treatment or care, and are able to make decisions at all stages – not just in the initial stage. This includes circumstances in which an initial decision may be to take no action.

102 If the treatment is ongoing, you should make sure there are clear arrangements in place to review decisions and, if necessary, to make new ones.

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