



Consent: patients and doctors making decisions together

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The duties of a doctor registered with the General Medical Council

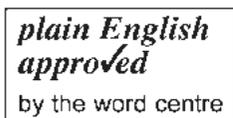
Patients must be able to trust doctors with their lives and health. To justify that trust you must show respect for human life and you must:

- Make the care of your patient your first concern
- Protect and promote the health of patients and the public
- Provide a good standard of practice and care
 - Keep your professional knowledge and skills up to date
 - Recognise and work within the limits of your competence
 - Work with colleagues in the ways that best serve patients' interests
- Treat patients as individuals and respect their dignity
 - Treat patients politely and considerately
 - Respect patients' right to confidentiality
- Work in partnership with patients
 - Listen to patients and respond to their concerns and preferences
 - Give patients the information they want or need in a way they can understand
 - Respect patients' right to reach decisions with you about their treatment and care
 - Support patients in caring for themselves to improve and maintain their health
- Be honest and open and act with integrity
 - Act without delay if you have good reason to believe that you or a colleague may be putting patients at risk
 - Never discriminate unfairly against patients or colleagues
 - Never abuse your patients' trust in you or the public's trust in the profession.

You are personally accountable for your professional practice and must always be prepared to justify your decisions and actions.

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This guidance came into effect on 2 June 2008



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About the guidance

This guidance, *Consent: patients and doctors making decisions together*, replaces the booklet *Seeking patients' consent: the ethical considerations* (1998). It expands on the guidance in *Good Medical Practice*, which requires doctors to be satisfied that they have consent from a patient, or other valid authority, before undertaking any examination or investigation, providing treatment, or involving patients in teaching and research.

This guidance sets out the principles on which good clinical decisions should be based. It provides a framework for good practice that covers the various situations that doctors may face in the course of their work. The guidance concentrates on decision-making in the context of investigations or treatment; but the principles apply more widely, including decisions on taking part in research, and decisions at the end of life. More detailed advice on these matters will be provided in separate guidance.

This guidance does not cover doctors' responsibilities to protect or disclose personal information about patients. See our publication, *Confidentiality* (2009).

As the law relating to decision-making and consent, particularly for patients who lack capacity, varies across the UK, doctors need to understand the law as it applies where they work (see paragraphs 62–63). This guidance takes account of, and is consistent with, current law across the UK. The legal annex gives more detail about relevant common law and legislation, and links to further information.

How the guidance applies to you

This guidance is addressed to doctors, but may also help patients and the public understand what to expect of their doctors.

In this guidance the terms 'you must' and 'you should' are used in the following ways:

- 'you must' is used for an overriding duty or principle
- 'you should' is used when we are providing an explanation of how you will meet the overriding duty
- 'you should' is also used where the duty or principle will not apply in all situations or circumstances, or where there are factors outside your control that affect whether or how you can comply with the guidance.

The guidance is not, and cannot be, exhaustive. So you should use your judgement to apply the principles it sets out to the situations you face in your own practice.

You must work in partnership with your patients. You should discuss with them their condition and treatment options in a way they can understand, and respect their right to make decisions about their care. You should see getting their consent as an important part of the process of discussion and decision-making, rather than as something that happens in isolation.

In deciding how much information to share with your patients you should take account of their wishes. The information you share should be in proportion to the nature of their condition, the complexity of the proposed investigation or treatment, and the seriousness of any potential side effects, complications or other risks.

Serious or persistent failure to follow this guidance will put your registration at risk. You must, therefore, be prepared to explain and justify your actions.

Part 1: Principles

- 1 All healthcare involves decisions made by patients and those providing their care. This guidance sets out principles for good practice in making decisions. The principles apply to all decisions about care: from the treatment of minor and self-limiting conditions, to major interventions with significant risks or side effects. The principles also apply to decisions about screening.¹

- 2 Whatever the context in which medical decisions are made, you must work in partnership with your patients to ensure good care. In so doing, you must:
 - (a) listen to patients and respect their views about their health
 - (b) discuss with patients what their diagnosis, prognosis, treatment and care involve
 - (c) share with patients the information they want or need in order to make decisions
 - (d) maximise patients' opportunities, and their ability, to make decisions for themselves
 - (e) respect patients' decisions.

Partnership

- 3 For a relationship between doctor and patient to be effective, it should be a partnership based on openness, trust and good communication. Each person has a role to play in making decisions about treatment or care.
- 4 No single approach to discussions about treatment or care will suit every patient, or apply in all circumstances. Individual patients may want more or less information or involvement in making decisions depending on their circumstances or wishes. And some patients may need additional support to understand information and express their views and preferences.
- 5 If patients have capacity to make decisions for themselves, a basic model applies:
 - (a) The doctor and patient make an assessment of the patient's condition, taking into account the patient's medical history, views, experience and knowledge.
 - (b) The doctor uses specialist knowledge and experience and clinical judgement, and the patient's views and understanding of their condition, to identify which investigations or treatments are likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, risks, burdens and side effects of each option, including the option to have no treatment. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.

- (c) The patient weighs up the potential benefits, risks and burdens of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which one. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor, or for no reason at all.²
 - (d) If the patient asks for a treatment that the doctor considers would not be of overall benefit to them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after discussion, the doctor still considers that the treatment would not be of overall benefit to the patient, they do not have to provide the treatment. But they should explain their reasons to the patient, and explain any other options that are available, including the option to seek a second opinion.
- 6 If patients are not able to make decisions for themselves, the doctor must work with those close to the patient and with other members of the healthcare team. The doctor must take into account any views or preferences expressed by the patient and must follow the law on decision-making when a patient lacks capacity.³

Part 2: Making decisions about investigations and treatment

Sharing information and discussing treatment options

- 7** The exchange of information between doctor and patient is central to good decision-making. How much information you share with patients will vary, depending on their individual circumstances. You should tailor your approach to discussions with patients according to:
- (a) their needs, wishes and priorities
 - (b) their level of knowledge about, and understanding of, their condition, prognosis and the treatment options
 - (c) the nature of their condition
 - (d) the complexity of the treatment, and
 - (e) the nature and level of risk associated with the investigation or treatment.
- 8** You should not make assumptions about:
- (a) the information a patient might want or need
 - (b) the clinical or other factors a patient might consider significant, or
 - (c) a patient's level of knowledge or understanding of what is proposed.

- 9** You must give patients the information they want or need about:
- (a) the diagnosis and prognosis
 - (b) any uncertainties about the diagnosis or prognosis, including options for further investigations
 - (c) options for treating or managing the condition, including the option not to treat
 - (d) the purpose of any proposed investigation or treatment and what it will involve
 - (e) the potential benefits, risks and burdens, and the likelihood of success, for each option; this should include information, if available, about whether the benefits or risks are affected by which organisation or doctor is chosen to provide care
 - (f) whether a proposed investigation or treatment is part of a research programme or is an innovative treatment designed specifically for their benefit⁴
 - (g) the people who will be mainly responsible for and involved in their care, what their roles are, and to what extent students may be involved
 - (h) their right to refuse to take part in teaching or research
 - (i) their right to seek a second opinion
 - (j) any bills they will have to pay
 - (k) any conflicts of interest that you, or your organisation, may have
 - (l) any treatments that you believe have greater potential benefit for the patient than those you or your organisation can offer.
- 10** You should explore these matters with patients, listen to their concerns, ask for and respect their views, and encourage them to ask questions.

- 11** You should check whether patients have understood the information they have been given, and whether or not they would like more information before making a decision. You must make it clear that they can change their mind about a decision at any time.

Answering questions

- 12** You must answer patients' questions honestly and, as far as practical, answer as fully as they wish.

Reasons for not sharing information with patients

- 13** No one else can make a decision on behalf of an adult who has capacity.⁵ If a patient 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 explain that it is still important that they understand the options open to them, and what the treatment will involve. If they do not want this information, you should try to find out why.
- 14** If, after discussion, a patient still does not want to know in detail about their condition or the treatment, you should respect their wishes, as far as possible. But you must still give them the information they need in order to give their consent to a proposed investigation or treatment. This is likely to include what the investigation or treatment aims to achieve and what it will involve, for example: whether the procedure is invasive; what level of pain or discomfort they might experience, and what can be done to minimise it; anything they should do to prepare for the investigation or treatment; and if it involves any serious risks.

- 15** If a patient insists that they do not want even this basic information, you must explain the potential consequences of them not having it, particularly if it might mean that their consent is not valid. 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.
- 16** You should not withhold information necessary for making decisions for any other reason, including when a relative, partner, friend or carer asks you to, unless you believe that giving it would cause the patient serious harm. In this context 'serious harm' means more than that the patient might become upset or decide to refuse treatment.
- 17** If you withhold information from the patient you must record your reason for doing so in the patient's medical records, and you must be prepared to explain and justify your decision. You should regularly review your decision, and consider whether you could give information to the patient later, without causing them serious harm.

Sharing information

- 18** How you discuss a patient's diagnosis, prognosis and treatment options is often as important as the information itself. You should:

 - (a)** share information in a way that the patient can understand and, whenever possible, in a place and at a time when they are best able to understand and retain it
 - (b)** give information that the patient may find distressing in a considerate way

- (c) involve other members of the healthcare team in discussions with the patient, if appropriate⁶
 - (d) 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
 - (e) 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.
- 19** You should give information to patients in a balanced way. If you recommend a particular treatment or course of action, you should explain your reasons for doing so. But you must not put pressure on a patient to accept your advice.
- 20** You may need to support your discussions with patients by using written material, or visual or other aids. If you do, you must make sure the material is accurate and up to date.
- 21** You should check whether the patient needs any additional support to understand information, to communicate their wishes, or to make a decision. You should bear in mind that some barriers to understanding and communication may not be obvious; for example, a patient may have unspoken anxieties, or may be affected by pain or other underlying problems. You must make sure, wherever practical, that arrangements are made to give the patient any necessary support. This might include, for example: using an advocate or interpreter; asking those close to the patient about the patient's communication needs; or giving the patient a written or audio record of the discussion and any decisions that were made.

Involving families, carers and advocates

- 22** You should accommodate a patient's wishes if they want another person, such as a relative, partner, friend, carer or advocate, to be involved in discussions or to help them make decisions. In these circumstances, you should follow the guidance in paragraphs 7–21.

Obstacles to sharing information

- 23** It is sometimes difficult, because of pressures on your time or the limited resources available, to give patients as much information or support in making decisions as you, or they, would like. To help in this, you should consider the role that other members of the healthcare team might play, and what other sources of information and support are available. These may be, for example, patient information leaflets, advocacy services, expert patient programmes, or support groups for people with specific conditions.
- 24** You should do your best to make sure that patients with additional needs, such as those with disabilities, have the time and support they need to make a decision. In all cases, you must treat patients fairly and not discriminate against them.
- 25** If you think that limits on your ability to give patients the time or information they need is seriously compromising their ability to make an informed decision, you should raise your concerns with your employing or contracting authority. See paragraph 6 of *Good Medical Practice* and the supplementary guidance, *Raising concerns about patient safety*.⁷

Responsibility for seeking a patient's consent

- 26** If you are the doctor undertaking an investigation or providing treatment, it is your responsibility to discuss it with the patient. If this is not practical, you can delegate the responsibility to someone else, provided you make sure that the person you delegate to:
- (a) is suitably trained and qualified
 - (b) has sufficient knowledge of the proposed investigation or treatment, and understands the risks involved
 - (c) understands, and agrees to act in accordance with, the guidance in this booklet.
- 27** If you delegate, you are still responsible for making sure that the patient has been given enough time and information to make an informed decision, and has given their consent, before you start any investigation or treatment.

Discussing side effects, complications and other risks

28 Clear, accurate information about the risks of any proposed investigation or treatment, presented in a way patients can understand, can help them make informed decisions. The amount of information about risk that you should share with patients will depend on the individual patient and what they want or need to know. Your discussions with patients should focus on their individual situation and the risk to them.

29 In order to have effective discussions with patients about risk, you must identify the adverse outcomes that may result from the proposed options. This includes the potential outcome of taking no action. Risks can take a number of forms, but will usually be:

- (a) side effects
- (b) complications
- (c) failure of an intervention to achieve the desired aim.

Risks can vary from common but minor side effects, to rare but serious adverse outcomes possibly resulting in permanent disability or death.

30 In assessing the risk to an individual patient, you must consider the nature of the patient's condition, their general health and other circumstances. These are variable factors that may affect the likelihood of adverse outcomes occurring.

- 31** You should do your best to understand the patient's views and preferences about any proposed investigation or treatment, and the adverse outcomes they are most concerned about. You must not make assumptions about a patient's understanding of risk or the importance they attach to different outcomes. You should discuss these issues with your patient.⁸
- 32** You must tell patients if an investigation or treatment might result in a serious adverse outcome,⁹ even if the likelihood is very small. You should also tell patients about less serious side effects or complications if they occur frequently, and explain what the patient should do if they experience any of them.
- 33** You must give information about risk in a balanced way. You should avoid bias, and you should explain the expected benefits as well as the potential burdens and risks of any proposed investigation or treatment.
- 34** You must use clear, simple and consistent language when discussing risks with patients. You should be aware that patients may understand information about risk differently from you. You should check that the patient understands the terms that you use, particularly when describing the seriousness, frequency and likelihood of an adverse outcome. You should use simple and accurate written information or visual or other aids to explain risk, if they will help the patient to understand.
- 35** If a patient does not want to know about the possible risks of a proposed investigation or treatment, you must follow the guidance in paragraphs 13–17.
- 36** You must keep up to date with developments in your area of practice, which may affect your knowledge and understanding of the risks associated with the investigations or treatments that you provide.

Making decisions

The scope of decisions

- 37** You must explain clearly to patients the scope of any decisions to be made. This will apply particularly if:
- (a)** treatment will 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 investigations or treatments are involved
 - (d)** uncertainty about the diagnosis or the options might only be resolved when the investigation or treatment has started, when the patient may be unable to make decisions.*
- 38** In such cases, you should discuss and agree with the patient how decisions will be made about whether to make changes to the investigation or treatment plan. You should establish whether the patient agrees to all or only parts of the proposed plan. If they agree only to parts of it, you should make sure that there is a clear process through which they can be involved in making decisions at a later stage.
- 39** 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 paragraph 79.

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

Making decisions about potential future events

- 40** You should discuss with patients the possibility of additional problems coming to light during an investigation or treatment when they might not be in a position to make a decision about how to proceed. If there is a significant risk of a particular problem arising, you should ask in advance what the patient would like you to do if it does arise. You should also ask if there are any procedures they object to, or which they would like more time to think about.

Ensuring that decisions are voluntary

- 41** Patients may be put under pressure by employers, insurers, relatives or others, to accept a particular investigation or treatment. You should be aware of this and of other situations in which patients may be vulnerable. Such situations may be, for example, if they are resident in a care home, subject to mental health legislation, detained by the police or immigration services, or in prison.
- 42** You should do your best to make sure that such patients have considered the available options and reached their own decision. If they have a right to refuse treatment, you should make sure that they know this and are able to refuse if they want to.

Respecting a patient's decisions

- 43** You must respect a patient's decision to refuse an investigation or treatment, even if you think their decision is wrong or irrational.¹⁰ You should explain your concerns clearly to the patient and outline the possible consequences of their decision. You must not, however, put pressure on a patient to accept your advice. If you are unsure about the patient's capacity to make a decision, you must follow the guidance in Part 3.

Expressions of consent

- 44** Before accepting a patient's consent, you must consider whether they have been given the information they want or need, and how well they understand the details and implications of what is proposed. This is more important than how their consent is expressed or recorded.
- 45** Patients can give consent orally or in writing, or they may imply consent by complying with the proposed examination or treatment, for example, by rolling up their sleeve to have their blood pressure taken.
- 46** In the case of minor or routine investigations or treatments, if you are satisfied that the patient understands what you propose to do and why, it is usually enough to have oral or implied consent.
- 47** In cases that involve higher risk, it is important that you get the patient's written consent. This is so that everyone involved understands what was explained and agreed.
- 48** By law you must get written consent for certain treatments, such as fertility treatment. You must follow the laws and codes of practice that govern these situations.

- 49** You should also get written consent from a patient if:
- (a) the investigation or treatment is complex or involves significant risks
 - (b) there may be significant consequences for the patient's employment, or social or personal life
 - (c) providing clinical care is not the primary purpose of the investigation or treatment
 - (d) the treatment is part of a research programme or is an innovative treatment designed specifically for their benefit.
- 50** If it is not possible to get written consent, for example, in an emergency or if the patient needs the treatment to relieve serious pain or distress, you can rely on oral consent. But you must still give the patient the information they want or need to make a decision. You must record the fact that they have given consent, in their medical records.

Recording decisions

- 51** You must use the patient's medical records or a consent form to record the key elements of your discussion with the patient. This should include the information you discussed, any specific requests by the patient, any written, visual or audio information given to the patient, and details of any decisions that were made.

Reviewing decisions

- 52** Before beginning treatment, you or a member of the healthcare team should check that the patient still wants to go ahead; and you must respond to any new or repeated concerns or questions they raise. This is particularly important if:
- (a)** significant time has passed since the initial decision was made
 - (b)** there have been material changes in the patient's condition, or in any aspect of the proposed investigation or treatment
 - (c)** new information has become available, for example about the risks of treatment or about other treatment options.
- 53** You must make sure that patients are kept informed about the progress of their treatment, and are able to make decisions at all stages, not just in the initial stage. If the treatment is ongoing, you should make sure that there are clear arrangements in place to review decisions and, if necessary, to make new ones.

Involving children and young people in making decisions

- 54** You should involve children and young people as much as possible in discussions about their care, even if they are not able to make decisions on their own.
- 55** A young person's ability to make decisions depends more on their ability to understand and weigh up options, than on their age. When assessing a young person's capacity to make decisions, you should bear in mind that:
- (a) a young person under 16 may have capacity to make decisions, depending on their maturity and ability to understand what is involved
 - (b) at 16 a young person can be presumed to have capacity to make most decisions about their treatment and care.
- 56** You must follow the guidance in *0-18 years: guidance for all doctors*, and in particular the section *Making decisions* (paragraphs 22–41). It gives advice on involving children and young people in decisions, assessing capacity and best interests, and what to do if they refuse treatment. It also explains the different legal requirements across the UK for decision-making involving children and young people.

Advance care planning

57 If a patient:

- (a) has a condition that will affect the length or quality of their life, or
- (b) has a condition that will impair their capacity as it progresses, such as dementia, or
- (c) is otherwise facing a situation in which loss or impairment of capacity is a foreseeable possibility

you should encourage them to think about what they might want for themselves in the event that they cannot make their own decisions, and to discuss their wishes and concerns with you and the healthcare team.

58 Such discussions might cover:

- (a) the patient's wishes, preferences or fears in relation to their future care, including any treatments they would want to refuse, and under what circumstances
- (b) the feelings, beliefs or values that may be influencing the patient's preferences and decisions
- (c) the relatives, friends, carers or representatives that the patient would like to be involved in decisions about their care
- (d) interventions that are likely to become necessary in an emergency, such as cardio-pulmonary resuscitation (CPR).

- 59** You should approach such discussions sensitively. If the patient agrees, you should consider involving other members of the healthcare team, people who are close to the patient or an advocate.
- 60** If a patient wants to nominate someone to make decisions on their behalf if they lose capacity, or if they want to refuse a particular treatment, you should explain that there may be ways to formalise these wishes and recommend that they get independent advice on how to do this.
- 61** You must record the discussion and any decisions the patient makes. You should make sure that a record of the plan is made available to the patient and others involved in their care, so that everyone is clear about what has been agreed. This is particularly important if the patient has made an advance decision to refuse treatment.¹¹ You should bear in mind that care plans need to be reviewed and updated as the situation or the patient's views change.

Part 3: Capacity issues

The legal framework

- 62** Making decisions about treatment and care for patients who lack capacity is governed in England and Wales by the *Mental Capacity Act 2005*, and in Scotland by the *Adults with Incapacity (Scotland) Act 2000*. The legislation sets out the criteria and procedures to be followed in making decisions when patients lack capacity to make these decisions for themselves. It also grants legal authority to certain people to make decisions on behalf of patients who lack capacity.¹² In Northern Ireland, there is currently no relevant primary legislation; and decision-making for patients without capacity is governed by the common law, which requires that decisions must be made in a patient's best interests.¹³ There is more information about legislation and case law in the legal annex to this guidance.¹⁴
- 63** The guidance that follows is consistent with the law across the UK. It is important that you keep up to date with, and comply with, the laws and codes of practice that apply where you work. If you are unsure about how the law applies in a particular situation, you should consult your defence body or professional association, or seek independent legal advice.

Presumption of capacity

- 64** You must work on 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 or treatment. You must only regard a patient as lacking capacity once it is clear that, having been given all appropriate help and support, they cannot understand, retain, use or weigh up the information needed to make that decision, or communicate their wishes.
- 65** You must not assume that a patient lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including mental illness), their beliefs, their apparent inability to communicate, or the fact that they make a decision that you disagree with.

Maximising a patient's ability to make decisions

- 66** A patient's ability to make decisions may depend on the nature and severity of their condition, or the difficulty or complexity of the decision. Some patients will always 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, because fluctuations in their condition impair their ability to understand, retain or weigh up information, or communicate their wishes.
- 67** If a patient's capacity is affected in this way, you must follow the guidance in paragraphs 18–21, taking particular care to give the patient the time and support they need to maximise their ability to make decisions for themselves. For example, you will need to think carefully about the extra support needed by patients with dementia or learning disabilities.
- 68** You must take all reasonable steps to plan for foreseeable changes in a patient's capacity to make decisions. This means that you should:
- (a)** discuss treatment options in a place and at a time when the patient is best able to understand and retain the information
 - (b)** ask the patient if there is anything that would help them remember information, or make it easier to make a decision; such as bringing a relative, partner, friend, carer or advocate to consultations, or having written or audio information about their condition or the proposed investigation or treatment
 - (c)** speak to those close to the patient and to other healthcare staff about the best ways of communicating with the patient, taking account of confidentiality issues.

- 69** If a patient is likely to have difficulty retaining information, you should offer them a written record of your discussions, detailing what decisions were made and why.
- 70** You should record any decisions that are 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.

Assessing capacity

- 71** You must assess a patient's capacity to make a particular decision at the time it needs to be made. 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.
- 72** You must take account of the advice on assessing capacity in the Codes of Practice that accompany the *Mental Capacity Act 2005* and the *Adults with Incapacity (Scotland) Act 2000* and other relevant guidance. If your assessment is that the patient's capacity is borderline, you must be able to show that it is more likely than not that they lack capacity.
- 73** If your assessment leaves you in doubt about the patient's capacity to make a decision, you should seek 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 decisions and their particular communication needs
 - (b)** colleagues with relevant specialist experience, such as psychiatrists, neurologists, or speech and language therapists.
- 74** If you are still unsure about the patient's capacity to make a decision, you must seek legal advice with a view to asking a court to determine capacity.

Making decisions when a patient lacks capacity

- 75** In making decisions about the treatment and care of patients who lack capacity, you must:
- (a) make the care of your patient your first concern
 - (b) treat patients as individuals and respect their dignity
 - (c) support and encourage patients to be involved, as far as they want to and are able, in decisions about their treatment and care
 - (d) treat patients with respect and not discriminate against them.
- 76** You must also consider:
- (a) whether the patient's lack of capacity is temporary or permanent
 - (b) which options for treatment would provide overall clinical benefit for the patient
 - (c) which option, including the option not to treat, would be least restrictive of the patient's future choices
 - (d) any evidence of the patient's previously expressed preferences, such as an advance statement or decision¹⁵
 - (e) the views of anyone the patient asks you to consult, or who has legal authority to make a decision on their behalf,¹⁶ or has been appointed to represent them¹⁷
 - (f) the views of people close to the patient on the patient's preferences, feelings, beliefs and values, and whether they consider the proposed treatment to be in the patient's best interests¹⁸
 - (g) what you and the rest of the healthcare team know about the patient's wishes, feelings, beliefs and values.

Resolving disagreements

77 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. Sometimes disagreements arise between members of the healthcare team, or between the healthcare team and those close to the patient. It is usually possible to resolve them, for example by involving an independent advocate, consulting a more experienced colleague, holding a case conference, or using local mediation services. You should take into account the different decision-making roles and authority of those you consult, and the legal framework for resolving disagreements.¹⁹

78 If, having taken these steps, there is still significant disagreement, you should seek legal advice on applying to the appropriate court or statutory body for review or for an independent ruling. Patients, those authorised to act for them, and those close to them, should be informed as early as possible of any decision to start such proceedings so that they have the opportunity to participate or be represented.

The scope of treatment in emergencies

79 When an emergency arises in a clinical setting²⁰ and it is not possible to find out a patient's wishes, you can treat them without their consent, provided the treatment is immediately necessary to save their life or to prevent a serious deterioration of their condition. The treatment you provide must be the least restrictive of the patient's future choices. For as long as the patient lacks capacity, you should provide ongoing care on the basis of the guidance in paragraphs 75–76. If the patient regains capacity while in your care, you should tell them what has been done, and why, as soon as they are sufficiently recovered to understand.

Legal annex

This section sets out some of the key elements of the law that deal with medical decisions, risk, capacity and consent. It is not intended to be a comprehensive list of relevant case law and legislation, nor is it a substitute for independent, up-to-date legal advice.

The cases cited are all relevant cases heard under English law. Although they are not binding in Scotland and Northern Ireland, they have 'persuasive authority', and are generally followed by the courts in these jurisdictions.

Common law

Risk

Chester v Afshar [2004] UKHL 41 Pt 2

The duty to warn patients about risk

Ms Carole Chester was left partially paralysed after surgery for lumbar disc protrusion. Dr Afshar had failed to warn Ms Chester that this was a foreseeable (1–2%) but unavoidable risk of the surgery. The House of Lords concluded that, though the failure to warn was not a direct cause of injury, it did result in negligence. In particular, Lord Bingham stated [para 16]:

A surgeon owes a general duty to a patient to warn him or her in general terms of possible serious risks involved in the procedure. The only qualification is that there may be wholly exceptional cases where objectively in the best interests of the patient the surgeon may be excused from giving a warning...In modern law medical paternalism no longer rules and a patient has a prima facie right to be informed by a surgeon of a small, but well-established, risk of serious injury as a result of surgery.

- Patients should be told of any possible significant adverse outcomes of a proposed treatment.
- In this case, a small but well-established risk of a serious adverse outcome was considered by the House of Lords to be 'significant'.

Refusal of treatment

Re C (Adult, refusal of treatment) [1994] 1 All ER 819

The right of a competent adult to refuse medical treatment/The principle that mental illness does not automatically call a patient's capacity into question.

C had paranoid schizophrenia and was detained in Broadmoor secure hospital. He developed gangrene in his leg but refused to agree to an amputation, which doctors considered was necessary to save his life. The Court upheld C's decision.

- The fact that a person has a mental illness does not automatically mean they lack capacity to make a decision about medical treatment.
- Patients who have capacity (that is, who can understand, believe, retain and weigh the necessary information) can make their own decisions to refuse treatment, even if those decisions appear irrational to the doctor or may place the patient's health or their life at risk.

Re MB (Adult, medical treatment) [1997] 38 BMLR 175 CA

Capacity to refuse treatment

MB needed a caesarean section, but panicked and withdrew consent at the last moment because of her needle phobia. The hospital obtained a judicial declaration that it would be lawful to carry out the procedure, a decision that MB appealed. However, she subsequently agreed to induction of anaesthesia and her baby was born by caesarean section.

The Court of Appeal upheld the judges' view that MB had not, at the time, been competent to refuse treatment, taking the view that her fear and panic had impaired her capacity to take in the information she was given about her condition and the proposed treatment. In assessing the case the judges reaffirmed the test of capacity set out in the *Re C* judgement.

- An individual's capacity to make particular decisions may fluctuate or be temporarily affected by factors such as pain, fear, confusion or the effects of medication.
- Assessment of capacity must be time and decision-specific.

Re B (Adult, refusal of medical treatment) [2002] 2 All ER 449

Right of a patient who has capacity to refuse life-prolonging treatment

B was a 43-year-old woman who had become tetraplegic and who no longer wished to be kept alive by means of artificial ventilation. She asked for ventilation to be withdrawn but the doctors caring for her were unwilling to agree to this. B, whose mental capacity was unimpaired by her illness, sought and obtained a declaration from the court that the hospital was acting unlawfully.

- A competent patient has the right to refuse treatment and their refusal must be respected, even if it will result in their death.

St George's Healthcare NHS Trust v S; R v Collins and others, ex parte S [1998] 3 All ER 673

The right of a competent pregnant woman to refuse treatment even if that refusal may result in harm to her or her unborn child/Application of the Mental Health Act 1983.

S was diagnosed with pre-eclampsia requiring admission to hospital and induction of labour, but refused treatment because she did not agree with medical intervention in pregnancy. Although competent and not suffering from a serious mental illness, S was detained for assessment under the Mental Health Act. A judge made a declaration overriding the need for her consent to treatment, and her baby was delivered by caesarean section.

The Appeal Court held that S's right to autonomy had been violated, her detention had been unlawful (since it had been motivated not by her mental state but by the need to treat her pre-eclampsia) and that the judicial authority for the caesarean had been based on false and incomplete information.

- A competent pregnant woman can refuse treatment even if that refusal may result in harm to her or her unborn child.
- Patients cannot lawfully be detained and compulsorily treated for a physical condition under the terms of the Mental Health Act.

Re T (Adult) [1992] 4 All ER 649

The effect of coercion/pressure on patient consent

T, a 20-year-old pregnant woman, was injured in a car accident and developed complications that required blood transfusions. She did not indicate on admission that she was opposed to receiving transfusions but after spending some time with her mother, who was a practising Jehovah's Witness, she decided to refuse the treatment.

The Court of Appeal considered that T had been pressurised by her mother and that her ability to decide about the transfusions was further impaired by the drugs with which she was being treated. The Court allowed the blood transfusions to proceed.

- A patient's consent to a particular treatment may not be valid if it is given under pressure or duress exerted by another person.

Requests for treatment

Mr Leslie Burke v GMC [2005] EWCA Civ 1003

This case concerned a wide range of issues, most of which related to decision-making at the end of life. However, for the purposes of this guidance, the key point is the Court of Appeal's opinion that doctors are under no legal or ethical obligation to agree to a patient's request for treatment if they consider the treatment is not in the patient's best interests.

Children and young people

Gillick v West Norfolk and Wisbech AHA [1986] AC 112

Children and young people's competence to consent to treatment

Mrs Gillick challenged the lawfulness of Department of Health guidance that doctors could provide contraceptive advice and treatment to girls under the age of 16 without parental consent or knowledge in some circumstances.

The House of Lords held that a doctor could give contraceptive advice and treatment to a young person under the age of 16 if:

- she had sufficient maturity and intelligence to understand the nature and implications of the proposed treatment
- she could not be persuaded to tell her parents or to allow her doctor to tell them
- she was very likely to begin or continue having sexual intercourse with or without contraceptive treatment
- her physical or mental health were likely to suffer unless she received the advice or treatment
- the advice or treatment was in the young person's best interests.

This case was specifically about contraceptive advice and treatment, but the case of *Axon, R (on the application of) v Secretary of State for Health [2006] EWHC 37 (Admin)* makes clear that the principles apply to decisions about treatment and care for sexually transmitted infections and abortion, too.

- As a result of this decision, a young person under 16 with capacity to make any relevant decision is often referred to as being 'Gillick competent'.

Legislation

Making decisions when patients lack capacity

England and Wales

Mental Capacity Act 2005

This Act provides a legal framework for making decisions in relation to people who lack capacity. It clarifies:

- who can make decisions, including decisions about medical care and treatment, for people who are unable to decide for themselves
- how those decisions should be made.

Section 1 of the Act sets out five statutory principles that apply to any action taken and decisions made under the Act. These are:

- (1) *a person must be assumed to have capacity unless it is established that they lack capacity*
- (2) *a person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success*
- (3) *a person is not to be treated as unable to make a decision merely because he makes an unwise decision*
- (4) *an act done, or decision made, under the Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests*
- (5) *before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.*

In this Act, people lack capacity in relation to a particular matter if, at the material time, they are unable to make a decision for themselves in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain (section 2(1)).

Doctors and other healthcare professionals must have regard to the supporting Code of Practice, which explains how the Act should work on a day to day basis and sets out the steps that those using and interpreting it should follow when:

- assessing a person's capacity, or
- reaching a decision in the best interests of a person who does not have capacity.

Mental Capacity Act 2005

www.opsi.gov.uk/acts/acts2005/20050009.htm

Mental Capacity Act Code of Practice

www.publicguardian.gov.uk/mca/code-of-practice.htm

Scotland

Adults with Incapacity (Scotland) Act 2000

This Act provides ways to help safeguard the welfare of people aged 16 and over who lack the capacity to take some or all decisions for themselves, because of a mental disorder or inability to communicate. It also allows other people to make decisions on their behalf. The Act provides various methods of intervening (that is, taking decisions or action) on behalf of an adult who lacks capacity, including in relation to healthcare. The Act sets out the principles that must be followed when deciding whether to intervene.

Any intervention must be:

- necessary and must benefit the person
- the minimum necessary to achieve the purpose.

Those making decisions must:

- take account of the person's present and past wishes and feelings, and must try every possible means of communicating with the person to find out what these are
- take into account the views of the person's nearest relative and primary carer, and of any other person with powers to intervene in the person's affairs or personal welfare, or with an interest in the person, so far as it is reasonable and practical to do so
- encourage the person to use any skills they have to make decisions
- consider whether it would be possible to intervene without using the Act.

In this Act, incapacity means being incapable of acting on, making, communicating, understanding, or remembering decisions by reason of mental disorder or inability to communicate due to physical disorder.

The Act is supported by Codes of Practice setting out guidance for those acting under the legislation, including doctors and other healthcare professionals who are treating adults with incapacity. Part 5 of the Code of Practice covers decisions about medical treatment and research.

Adults with Incapacity (Scotland) Act 2000

www.opsi.gov.uk/legislation/scotland/acts2000/20000004.htm

Scottish Government site for the Act

www.scotland.gov.uk/Topics/Justice/Civil/awi

Northern Ireland

There is currently no primary legislation on capacity covering Northern Ireland. Decisions about medical treatment and care when people lack capacity must be made in accordance with the common law, which requires decisions to be made in a person's best interests.

The *Bamford Review of Mental Health & Learning Disability (N.Ireland)* which produced its final report in August 2007 recommended that there should be a single comprehensive legislative framework for the reform of mental health legislation and the introduction of capacity legislation in Northern Ireland.

On 2 January 2009, the Northern Ireland Department of Health, Social Services and Public Safety (the Department) issued a consultation document, *Legislative Framework for Mental Capacity and Mental Health Legislation*. As a result of the consultation, the Department is now leading work on a single bill covering mental capacity and mental health to be introduced into the Northern Ireland Assembly in 2011.

The Bamford Review of Mental Health & Learning Disability (N. Ireland)

www.rmhdni.gov.uk/index.htm

Delivering the Bamford Vision: The Response of NI Executive to the Bamford Review of Mental Health and Learning Disability, Action Plan 2009-2011

www.dhsspsni.gov.uk/bamford_action_plan_2009-2011.pdf

Treatment for mental disorder without consent

England and Wales

Mental Health Act 1983 (as amended by the Mental Health Act 2007)

The Mental Health Act provides a statutory framework, which sets out when patients can be compulsorily treated for a mental disorder without consent, to protect them or others from harm. It also sets out the rights of patients to challenge the use of compulsory powers through the Mental Health Tribunal.

Mental Health Act 2007

www.opsi.gov.uk/acts/acts2007/ukpga_20070012_en_1

Scotland

Mental Health (Care and Treatment) (Scotland) Act 2003

This Act sets out the circumstances in which people with mental disorders can be compulsorily treated without their consent, for their mental disorder. As well as establishing compulsory powers, the Act sets up rights and safeguards for patients (including the Mental Health Tribunal and a right of access to independent advocacy services). One of the conditions for the use of compulsory powers under the Act is that the person's ability to make decisions about treatment for their mental disorder must be 'significantly impaired'.

Mental Health (Care and Treatment) (Scotland) Act 2003

www.opsi.gov.uk/legislation/scotland/acts2003/20030013.htm

Northern Ireland

Mental Health (NI) Order 1986

Article 69 of this Order in Council provides for treatment for mental disorder to be given to patients in certain circumstances without their consent.

The Executive is proposing to introduce a single bill governing mental capacity and mental health into the Assembly in 2011.

Mental Health (NI) Order 1986

www.opsi.gov.uk/SI/si2004/20041272.htm

Use of human tissue

England, Wales and Northern Ireland

Human Tissue Act 2004

The Act requires that consent is obtained before:

- a person's organs and tissue can be stored or used for purposes such as research, post-mortem examination, and transplantation
- a deceased person's organs and tissue can be removed for these purposes.²¹

The Act specifies whose consent is needed and in what circumstances. The Human Tissue Authority (HTA) publishes a Code of Practice which gives detailed advice on how consent should be obtained and recorded.

Human Tissue Act 2004

www.opsi.gov.uk/acts/acts2004/20040030.htm

Human Tissue Authority website - Codes of Practice

www.hta.gov.uk/guidance/codes_of_practice.cfm

Scotland

Human Tissue (Scotland) Act 2006

The Act requires that authorisation is obtained before a deceased person's organs and tissue can be stored or used for purposes such as research, post-mortem examination, and transplantation. It does not cover the use and storage of tissue from living people, other than organ donation for transplantation.

Human Tissue (Scotland) Act 2006

www.opsi.gov.uk/legislation/scotland/acts2006/20060004.htm

Fertility Treatments

Human Fertilisation and Embryology Act 1990 (as amended by the Human Fertilisation and Embryology Act 2008)

This Act provides a legal framework across the UK for all those involved in fertility treatments. It defines the rights of donors, patients and the children who may result from the treatment, restricts research on human and human admixed embryos to specified purposes and places time limits on the storage of embryos, eggs, and sperm. The Human Fertilisation and Embryology Authority (HFEA) was created under the Act to oversee the licensing and compliance of treatment clinics and research centres and to keep new developments under review.

Human Fertilisation and Embryology Act 1990 (as amended)

www.opsi.gov.uk/acts/acts1990/Ukpga_19900037_en_1.htm

Human Fertilisation and Embryology Act 2008

http://www.opsi.gov.uk/acts/acts2008/ukpga_20080022_en_1

Human Fertilisation and Embryology Authority website

www.hfea.gov.uk

Human Rights

The Human Rights Act 1998

The preamble to the *Human Rights Act 1998* (HRA) describes it as 'an Act to give greater effect to rights and freedoms guaranteed under the European Convention on Human Rights' (the Convention). The HRA only incorporates the rights in Articles 2 to 12 and in Article 14 of the Convention, plus those in the First and Sixth Protocols. The incorporated rights are set out in the First Schedule to the HRA and are referred to as 'Convention rights'.

As far as it is possible to do so, primary legislation and subordinate legislation must be read and given effect in a way that is compatible with these Convention rights.

The HRA requires that all public bodies must ensure that everything they do is compatible with the Convention rights unless an Act of Parliament makes that impossible. They must provide a way for people to challenge a public body if they believe it has acted, or proposes to act, in a way that is unlawful under the HRA.

The Convention Articles most likely to be relevant to decisions about medical investigations and treatment are:

- Article 2 (the right to life)
- Article 3 (the right to be free from inhuman or degrading treatment)
- Article 8 (the right to respect for privacy and family life)
- Article 10 (the right to freedom of expression, which includes the right to hold opinions and to receive information)
- Article 14 (the right to be free from discriminatory practice in respect of these rights).

Ministry of Justice Human Rights pages

www.justice.gov.uk/whatwedo/humanrights.htm

Other sources of information and guidance

All GMC guidance can be found on our website at

www.gmc-uk.org/guidance

General

Reference guide to consent for examination or treatment (Department of Health)

Reference guide to consent for examination, treatment or care (Department of Health, Social Services & Public Safety NI, 2003)

Reference Guide for Consent to Examination or Treatment (Welsh Assembly Government, 2008)

A Good Practice Guide on Consent for Health Professionals in NHS Scotland (Scottish Executive Health Department, 2006)

Communication and Information

Better information, better choices, better health: Putting information at the centre of health (Department of Health, 2004)

NHS Toolkit for producing patient information (Department of Health, 2003)

Supporting people with long-term conditions to self care (Department of Health, 2006)

Discussing Risk

Raising the Standard: Information for Patients (Royal College of Anaesthetists, February 2003)

Project: Explaining the risks and benefits of treatment options (Royal College of Physicians, Patient Involvement Unit, 2004–2006)

Consent in cardiac surgery: a good practice guide to agreeing and recording consent (Parliamentary and Health Service Ombudsman, Society for Cardiothoracic Surgeons of Great Britain and Ireland, 2005)

Capacity issues

Mental Capacity Act 2005 Code of Practice

Code of Practice for persons authorised to carry out medical treatment or research under Part 5 of the Adults with Incapacity (Scotland) Act 2000

The Mental Capacity Act 2005
Guidance for health professionals
(British Medical Association, 2007)

Medical treatment for adults with incapacity: guidance on ethical and medico-legal issues in Scotland (British Medical Association, 2002)

Guidance for Local Authorities: Provision of community care services to adults with incapacity (Scottish Executive, March 2007)

Mental Health

Consent to treatment: A guide for mental health practitioners (Mental Welfare Commission for Scotland)

What is the relationship between the Mental Capacity Act and the Mental Health Act 1983?, Chapter 13, *Mental Capacity Act 2005 Code of Practice*

Endnotes

- 1 Testing of healthy or asymptomatic people to detect genetic predispositions or early signs of debilitating or life-threatening conditions.
- 2 Mental health laws across the UK set out the circumstances in which an individual may be compulsorily assessed and treated for a mental disorder, without their consent. See the legal annex for more information about the legislation across the UK.
- 3 See paragraphs 62–63 and the legal annex for an overview of the relevant legislation.
- 4 The patient should be told how the proposed treatment differs from the usual methods, why it is being offered, and if there are any additional risks or uncertainties. If you are considering prescribing unlicensed medicines or medicines for use off-label, you must follow the guidance in paragraphs 19–24 of *Good practice in prescribing medicines*.
- 5 A patient has capacity if they can understand, retain, use and weigh up the information needed to make a decision, and can communicate their wishes – see paragraphs 71–74 on assessing capacity. If your patient is under 18 you must follow the guidance in paragraphs 54–56 and the GMC’s guidance, *0–18 years: guidance for all doctors*. In certain circumstances, a patient with capacity can be treated without their consent for a mental disorder, subject to the provisions of relevant mental health legislation – see the legal annex for more information about legislation across the UK.
- 6 Following the guidance in paragraphs 25–29 of *Confidentiality* (2009).

- ⁷ See also paragraph 19 of *Management for doctors* and the supplementary guidance, *Accountability in Multi-disciplinary and Multi-Agency Mental Health Teams* for more guidance on steps doctors can take to clarify responsibility and lines of accountability.
- ⁸ See *Explaining the risks and benefits of treatment options*, Royal College of Physicians Patient and Carer Involvement Steering Group, www.rcplondon.ac.uk
- ⁹ An adverse outcome resulting in death, permanent or long-term physical disability or disfigurement, medium or long-term pain, or admission to hospital; or other outcomes with a long-term or permanent effect on a patient's employment, social or personal life.
- ¹⁰ If the patient has a mental disorder, you should note the exceptions in the *Mental Health Act 1983* (as amended by the *Mental Health Act 2007*), the *Mental Health (NI) Order 1986*, and the *Mental Health (Care and Treatment) (Scotland) Act 2003*. They allow compulsory treatment for mental disorder in certain circumstances, without consent, even if the patient has capacity. See the legal annex for more information.

- 11 The *Mental Capacity Act 2005* requires advance decisions to refuse life-sustaining treatment to be in writing. Advance decisions to refuse other types of treatment may be written or verbal but, if verbal, they should be recorded in a person's healthcare record (see *Mental Capacity Act 2005 Code of Practice*, chapter 9). It may be helpful under the provisions of the *Adults with Incapacity (Scotland) Act 2000*, for a written record to be made of a person's advance decision to refuse medical treatment (see *Code of Practice for those authorised to carry out medical treatment or research under Part 5 of the Act, paragraphs 2.27–2.30*).
- 12 Individuals with powers of attorney that cover health and welfare decisions (England, Wales and Scotland), court-appointed deputies (England and Wales) or guardians with welfare powers (Scotland) can, in certain circumstances, make decisions on behalf of a person who does not have capacity. See the legal annex for more information.
- 13 In Northern Ireland, there is currently no legal provision for someone else to consent to treatment on behalf of patients without capacity.
- 14 If you are treating a patient who lacks capacity and who also has a mental disorder, you should be aware of how the mental health legislation across the UK interacts with the law on mental capacity. See Other sources of information and guidance.
- 15 See paragraphs 2.28 –2.29 of the *Code of Practice for persons authorised to carry out medical treatment or research under Part 5 of the Adults with Incapacity (Scotland) Act 2000*, or Chapter 9 of the *Mental Capacity Act 2005 Code of Practice*.
- 16 Welfare attorneys and court-appointed guardians (Scotland), holders of lasting powers of attorney and court-appointed deputies (England and Wales).

- 17 Independent Mental Capacity Advocates in England and Wales.
- 18 In England and in Wales, if you are proposing serious medical treatment (see paragraphs 10.42 – 10.50 of the *Mental Capacity Act 2005 Code of Practice*) and there is nobody other than paid staff who can represent the views of a patient who lacks the capacity to consent to that serious medical treatment, and that treatment is provided or funded by the NHS, an Independent Mental Capacity Advocate must be instructed to represent and support the patient.
- 19 See Chapter 3 of the *Code of Practice for persons authorised to carry out medical treatment or research under Part 5 of the Adults with Incapacity (Scotland) Act 2000*, or *Chapter 15 of the Mental Capacity Act 2005 Code of Practice*.
- 20 Paragraph 11 of *Good Medical Practice* says that doctors must offer assistance in an emergency, wherever it arises, taking account of their own safety, their competence and the availability of other options for care.
- 21 The removal of tissue from a person as part of their diagnosis or treatment does not fall within the scope of the Act and is covered by the usual legal and ethical requirements for consent to treatment.

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