

# *Tadley Medical Partnership*



## Policy for consent to Examination or Treatment

# Policy for consent to examination or treatment

## Why consent is crucial

1. Patients have a fundamental legal and ethical right to determine what happens to their own bodies. Valid consent to treatment is therefore absolutely central in all forms of healthcare, from providing personal care to undertaking major surgery. Seeking consent is also a matter of common courtesy between health professionals and patients.

## This policy

2. This policy sets out the standards and procedures in this Practice which aim to ensure that health professionals are able to comply with the guidance. This document is primarily concerned with healthcare but is also applicable to social care colleagues should also be aware of their obligations to obtain consent before providing certain forms of social care, such as those that involve touching the patient or client.

## What consent is – and isn't

3. "Consent" is a patient's agreement for a health professional to provide care. Patients may indicate consent non-verbally (for example by presenting their arm for their pulse to be taken), orally, or in writing. For the consent to be valid, the patient must:

- Have capacity to take the particular decision;
- have received sufficient information to take it; and
- not be acting under duress.

4. The context of consent can take many different forms, ranging from the active request by a patient of a particular treatment (which may or may not be appropriate or available) to the passive acceptance of a health professional's advice. In some cases, the health professional will suggest a particular form of treatment or investigation and after discussion the patient may agree to accept it. In others, there may be a number of ways of treating a condition and the health professional will help the patient to decide between them. Some patients, especially those with chronic conditions, become very well informed about their illness and may actively request particular treatments. In many cases, 'seeking consent' is better described as 'joint decision-making': the patient and health professional need to come to an agreement on the best way forward, based on the patient's values and preferences and the health professional's clinical knowledge.

5. Clinicians must work on the presumption that every adult patient has the capacity to make decisions about their care until proven otherwise.

6. Where an adult patient lacks the mental capacity (either temporarily or permanently) to give or withhold consent for themselves, treatment may be given without prior consent if it is in their best interests as long as it has not been refused in advance in a valid and applicable advance directive. Be aware that The Mental Capacity Act enables a person aged 18 or over to appoint an attorney to look after their health and welfare decisions if they should lack the capacity to make such decisions in the future. Under a personal welfare Lasting Power of Attorney (LPA), the attorney, if they have the authority to do so, can make decisions that are

as valid as those made by the person themselves. The LPA must be made in the form, and meet the criteria set out in the regulations and it must be registered with the Office of the Public Guardian before it can be used.

## Guidance on consent

7. The Department of Health has issued a number of guidance documents on consent, and these should be consulted for advice on the current law and good practice requirements in seeking consent. Health professionals must also be aware of any guidance on consent issued by their own regulatory bodies. Useful reference documents are:

- **12 key points on consent: the law in England.** This one-page document summarises those aspects of the law on consent which arise on a daily basis and is attached at Annex A.
- **Reference guide to consent for examination or treatment.** This provides a comprehensive summary of the current law on consent, and includes requirements of regulatory bodies such as the General Medical Council where these are more stringent. A copy of this document is to be retained with this policy for ease of reference.
- Specific guidance, incorporating both the law and good practice advice, is available for health professionals working with children, with people with learning disabilities and with older people.
- GMC's 'Consent: Patients and Doctors Making Decisions Together'.
- GMC's '0 – 18 Years: Guidance for All Doctors'.

## Documentation

8. For significant procedures, it is essential for health professionals to document clearly both a patient's agreement to the intervention and the discussions which led up to that agreement. This may be done either through the use of a consent form (with further detail in the patient's notes if necessary), or through documenting in the patient's notes that they have given oral consent.

## Written consent

9. Consent is often wrongly equated with a patient's signature on a consent form. A signature on a form is *evidence* that the patient has given consent, but is not *proof* of valid consent. If a patient is rushed into signing a form, on the basis of too little information, the consent may not be valid, despite the signature. Similarly, if a patient has given valid verbal consent, the fact that they are physically unable to sign the form is no bar to treatment. Patients may, if they wish, withdraw consent after they have signed a form: the signature is evidence of the process of consent-giving, not a binding contract.

10. It is rarely a legal requirement to seek written consent, but it is good practice to do so if any of the following circumstances apply:

- the treatment or procedure is complex, or involves significant risks (the term 'risk' is used throughout to refer to any adverse outcome, including those which some health professionals would describe as 'side-effects' or 'complications')
- providing clinical care is not the primary purpose of the procedure
- there may be significant consequences for the patient's employment, social or personal life

11. Completed forms should be scanned to the patient's notes. Any changes to a form, made after the form has been signed by the patient, should be initialed and dated by both patient and health professional.

12. It will not usually be necessary to obtain written consent from a patient for routine and low-risk procedures, such as providing personal care or taking a blood sample. However, if you have any reason to believe that the consent may be disputed later or if the procedure is of particular concern to the patient (for example if they have declined, or become very distressed about, similar care in the past), it would be helpful to do so.

### **Principles to follow when patients lack capacity to give or withhold consent**

13. Where an adult patient does not have the capacity to give or withhold consent to a significant intervention, this fact should be documented in Form 4 attached (form for adults who are unable to consent to investigation or treatment) and entered in the patient notes, along with the assessment of the patient's capacity, why the health professional believes the treatment to be in the patient's best interests, and the involvement of people close to the patient. The standard consent forms should never be used for adult patients unable to consent for themselves.

14. An apparent lack of capacity to give or withhold consent may in fact be the result of communication difficulties rather than genuine incapacity. You should involve appropriate colleagues in making such assessments of incapacity, such as specialist learning disability teams and speech and language therapists, unless the urgency of the patient's situation prevents this. If at all possible, the patient should be assisted to make and communicate their own decision, for example by providing information in non-verbal ways where appropriate.

15. 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.

16. Occasionally, there will not be a consensus on whether a particular treatment is in an incapacitated adult's best interests. Where the consequences of having, or not having, the treatment are potentially serious, a court declaration may be sought.

17. 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 GMC guidance '*Consent: patients and doctors making decisions together*', paragraphs 7–21.

18. You should take into account any prior expressions of wishes or consent.

## Availability of forms

19. Standard consent forms and forms for adults who are unable to consent for themselves are reproduced in Appendix B and are available in GP Forms. There are four versions:

- **Form 1** for adults or competent children
- **Form 2** for parental consent for a child or young person
- **Form 4** for use when patients lack the capacity to give or withhold consent.

## When should consent be sought?

20. When a patient formally gives their consent to a particular intervention, this is only the *endpoint* of the consent process. It is helpful to see the whole process of information provision, discussion and decision-making as part of 'seeking consent'. This process may take place at one time, or over a series of meetings and discussions, depending on the seriousness of what is proposed and the urgency of the patient's condition.

## Single stage process

21. In many cases, it will be appropriate for a health professional to initiate a procedure immediately after discussing it with the patient. For example, during an ongoing episode of care a doctor or nurse may suggest a particular treatment and explain how it might help the patient's condition and whether there are any significant risks. If the patient is willing for the technique to be used, they will then give their consent and the procedure can go ahead immediately. In many such cases, consent will be given orally.

22. If a proposed procedure carries significant risks, it will be appropriate to seek written consent, and health professionals must take into consideration whether the patient has had sufficient chance to absorb the information necessary for them to make their decision. As long as it is clear that the patient understands and consents, the health professional may then proceed.

## Two or more stage process

23. In cases where *written* consent is being sought, treatment options may be discussed in advance of the actual procedure being carried out. This may be on just one occasion or it might be over a whole series of consultations with a number of different health professionals. The consent process will therefore have at least two stages: the first being the provision of information, discussion of options and initial (oral) decision, and the second being confirmation that the patient still wants to go ahead. The consent form should be used as a means of documenting the information stage(s), as well as the confirmation stage.

24. Patients receiving elective treatment or investigations for which written consent is appropriate should be familiar with the contents of their consent form. They may be invited to sign the form, confirming that they wish treatment to go ahead, at any appropriate point before the procedure; at a prior consultation or when they arrive for treatment. If a form is signed before the patient arrives for treatment, a member of the healthcare team must check with the patient at this point whether they have any further concerns and whether their condition has changed. This is particularly important where there has been a significant lapse of time between the form being signed and the procedure. When confirming the patient's consent and understanding, it is advisable to use a form of words which requires more than a yes/no answer from the patient: for example beginning with "tell me what you're expecting to happen", rather than "is everything all right?"

25. While administrative arrangements will vary, it should always be remembered that for consent to be valid, the patient must feel that it would have been possible for them to refuse, or change their mind. It will rarely be appropriate to ask a patient to sign a consent form after they have begun to be prepared for treatment unless this is unavoidable because of the circumstances.

### **Seeking consent for local anesthesia**

26. Where local anesthesia is necessary as part of a patient's care, it is the doctor's responsibility to advise the patient that consent to treatment will include consent to local anesthesia.

### **Emergencies**

27. Clearly in emergencies, the two stages (discussion of options and confirmation that the patient wishes to go ahead) will follow straight on from each other and it may often be appropriate to use the patient's notes to document any discussion and the patient's consent, rather than using a form. The urgency of the patient's situation may limit the quantity of information that they can be given, but should not affect its quality.

### **Treatment of young children**

28. Only people with 'parental responsibility' are entitled to give consent on behalf of their children. You must be aware that not all parents have parental responsibility for their children. If you are in any doubt about whether the person with the child has parental responsibility for that child, you must check; see GMC Guidance '*0 – 18 years: guidance for all doctors*'.

### **Provision of information**

29. The provision of information is central to the consent process. Before patients can come to a decision about treatment, they need comprehensible information about their condition and about possible treatments/investigations and their risks and benefits (including the risks/benefits of doing nothing). They also need to know whether additional procedures are likely to be necessary as part of the procedure, for example the removal of particular tissue.

Once a decision to have a particular treatment/investigation has been made, patients need information about what will happen, how they will feel afterwards and so on.

30. Patients and those close to them will vary in how much information they want: from those who want as much detail as possible, including details of rare risks, to those who ask health professionals to make decisions for them. There will always be an element of clinical judgment in determining what information should be given. However, the presumption must be that the patient wishes to be well informed about the risks and benefits of the various options. Where the patient makes clear (verbally or non-verbally) that they do not wish to be given this level of information, this should be documented in the patient's notes.

### **Access to health professionals between formal appointments**

31 After an appointment with a health professional in primary care, patients will often think of further questions which they would like answered before they take their decision. Where possible, it will be much quicker and easier for the patient to contact the healthcare team by telephone than to make another appointment and a telephone consultation should be given where appropriate.

### **Who is responsible for seeking consent?**

32. The health professional carrying out the procedure is ultimately responsible for ensuring that the patient is genuinely consenting to what is being done: it is they who will be held responsible in law if this is challenged later.

33. Where oral or non-verbal consent is being sought at the point the procedure will be carried out, this will naturally be done by the health professional responsible. However, team work is a crucial part of the way the NHS operates, and where written consent is being sought it may be appropriate for other members of the team to participate in the process of seeking consent.

### **Completing consent forms**

34. The standard consent form provides space for a health professional to provide information to patients and to sign confirming that they have done so. The health professional providing the information must be competent to do so: either because they themselves carry out the procedure, or because they have received appropriate training in advising patients about this procedure, have been assessed, are aware of their own knowledge limitations and are subject to audit.

35. If the patient signs the form in advance of the procedure, a health professional involved in their care on the day should sign the form to confirm that the patient still wishes to go ahead and has had any further questions answered. It will be appropriate for any member of the healthcare team (for example a nurse admitting the patient for an elective procedure) to provide the second signature, as long as they have access to appropriate colleagues to answer questions they cannot handle themselves.

### **Responsibility of health professionals**

36. It is a health professional's own responsibility:

- to ensure that when they require colleagues to seek consent on their behalf they are confident that the colleague is competent to do so; and
- to work within their own competence and not to agree to perform tasks which exceed that competence.

37. If you feel that you are being pressurised to seek consent when you do not feel competent to do so, you should inform the clinical governance lead (currently Dr RE Walker) or the Practice Manager.

## **Refusal of treatment**

38. If the process of seeking consent is to be a meaningful one, refusal must be one of the patient's options. A competent adult patient is entitled to refuse any treatment, except in circumstances governed by the *Mental Health Act 1983*. The situation for children is more complex: see the Department of Health's *Seeking consent: working with children* for more detail. The following paragraphs apply primarily to adults.

39. If, after discussion of possible treatment options, a patient refuses all treatment, this fact should be clearly documented in their notes. If the patient has already signed a consent form, but then changes their mind, you (and where possible the patient) should note this on the form.

40. Where a patient has refused a particular intervention, you must ensure that you continue to provide any other appropriate care to which they have consented. You should also ensure that the patient realises they are free to change their mind and accept treatment if they later wish to do so. Where delay may affect their treatment choices, they should be advised accordingly.

41. If a patient consents to a particular procedure but refuses certain aspects of the intervention, you must explain to the patient the possible consequences of their partial refusal. If you genuinely believe that the procedure cannot be safely carried out under the patient's stipulated conditions, you are not obliged to perform it. You must, however, continue to provide any other appropriate care. Where another health professional believes that the treatment can be safely carried out under the conditions specified by the patient, you must on request be prepared to transfer the patient's care to that health professional.

42. You must respect a patient's decision to refuse an investigation or treatment, even if you think their decision is wrong or irrational. 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.

## **Clinical photography and conventional or digital video recordings**

43. Photographic and video recordings made for clinical purposes form part of a patient's record. Although consent to certain recordings, such as Xrays, is implicit in the patient's consent to the procedure, health professionals should always ensure that they make clear in advance if any photographic or video recording will result from that procedure.

44. Photographic and video recordings which are made for treating or assessing a patient must not be used for any purpose other than the patient's care or the audit of that care, without the express consent of the patient or a person with parental responsibility for the patient. The one exception to this principle is set out below. If you wish to use such a recording for education, publication or research purposes, you must seek consent in writing, ensuring that the person giving consent is fully aware of the possible uses of the material. In particular, the person must be made aware that you may not be able to control future use of the material once it has been placed in the public domain. If a child is not willing for a recording to be used, you must not use it, even if a person with parental responsibility consents.

45. Photographic and video recordings, made for treating or assessing a patient and from which there is no possibility that the patient might be recognised, may be used within the clinical setting for education or research purposes without express consent from the patient, as long as this policy is well publicised. However, express consent must be sought for any form of publication.

46. If you wish to make a photographic or video recording of a patient specifically for education, publication or research purposes, you must first seek their written consent (or where appropriate that of a person with parental responsibility) to make the recording, and then seek their consent to use it. Patients must know that they are free to stop the recording at any time and that they are entitled to view it if they wish, before deciding whether to give consent to its use. If the patient decides that they are not happy for any recording to be used, it must be destroyed. As with recordings made with therapeutic intent, patients must receive full information on the possible future uses of the recording, including the fact that it may not be possible to withdraw it once it is in the public domain.

47. The situation may sometimes arise where you wish to make a recording specifically for education, publication or research purposes, but the patient is temporarily unable to give or withhold consent because, for example, they are unconscious. In such cases, you may make such a recording, but you must seek consent as soon as the patient regains capacity. You must not use the recording until you have received consent for its use, and if the patient does not consent to any form of use, the recording must be destroyed.

48. If the patient is likely to be permanently unable to give or withhold consent for a recording to be made, you should seek the agreement of some-one close to the patient. You must not make any use of the recording which might be against the interests of the patient. You should also not make, or use, any such recording if the purpose of the recording could equally well be met by recording patients who are able to give or withhold consent.

## **Training**

49. In addition to complying with this policy, all partners and members of staff are to be will be advised/reminded of any consent issues no less than annually in either a formal or informal setting.

## **Policy Review**

50. This policy is to be reviewed annually.

List of Annexes:

Annex A – 12 key points on consent: the law in England

Annex B – Consent Forms

Annex C – Information for Patients about Consent

Annex D – GMC Guidance 'Consent: patients and doctors making decisions together'.

Annex E – GMC Guidance '0 – 18 years: guidance for all doctors'.

## **12 key points on consent: the law in England**

### **When do health professionals need consent from patients?**

1. Before you examine, treat or care for competent adult patients you must obtain their consent.
2. Adults are always assumed to be competent unless demonstrated otherwise. If you have doubts about their competence, the question to ask is: "can this patient understand and weigh up the information needed to make this decision?" Unexpected decisions do not prove the patient is incompetent, but may indicate a need for further information or explanation.
3. Patients may be competent to make some health care decisions, even if they are not competent to make others.
4. Giving and obtaining consent is usually a process, not a one-off event. Patients can change their minds and withdraw consent at any time. If there is any doubt, you should always check that the patient still consents to your caring for or treating them.

### **Can children give consent for themselves?**

5. Before examining, treating or caring for a child, you must also seek consent. Young people aged 16 and 17 are presumed to have the competence to give consent for themselves. Younger children who understand fully what is involved in the proposed procedure can also give consent (although their parents will ideally be involved). In other cases, some-one with parental responsibility must give consent on the child's behalf, unless they cannot be reached in an emergency. If a competent child consents to treatment, a parent **cannot** over-ride that consent. Legally, a parent can consent if a competent child refuses, but it is likely that taking such a serious step will be rare.

### **Who is the right person to seek consent?**

6. It is always best for the person actually treating the patient to seek the patient's consent. However, you may seek consent on behalf of colleagues if you are capable of performing the procedure in question, or if you have been specially trained to seek consent for that procedure.

### **What information should be provided?**

7. Patients need sufficient information before they can decide whether to give their consent: for example information about the benefits and risks of the proposed treatment, and alternative treatments. If the patient is not offered as much information as they reasonably need to make their decision, and in a form they can understand, their consent may not be valid.

8. Consent must be given voluntarily: not under any form of duress or undue influence from health professionals, family or friends.

### **Does it matter how the patient gives consent?**

9. No: consent can be written, oral or non-verbal. A signature on a consent form does not itself prove the consent is valid – the point of the form is to record the patient's decision, and also increasingly the discussions that have taken place. Your Trust or organisation may have a policy setting out when you need to obtain written consent.

### **Refusal of treatment**

10. Competent adult patients are entitled to refuse treatment, even when it would clearly benefit their health. The only exception to this rule is where the treatment is for a mental disorder and the patient is detained under the Mental Health Act 1983. A competent pregnant woman may refuse any treatment, even if this would be detrimental to the fetus.

### **Adults who are not competent to give consent**

11. **No-one** can give consent on behalf of an incompetent adult. However, you may still treat such a patient if the treatment would be in their best interests. 'Best interests' go wider than best medical interests, to include factors such as the wishes and beliefs of the patient when competent, their current wishes, their general wellbeing and their spiritual and religious welfare. People close to the patient may be able to give you information on some of these factors. Where the patient has never been competent, relatives, carers and friends may be best placed to advise on the patient's needs and preferences.

12. If an incompetent patient has clearly indicated in the past, while competent, that they would refuse treatment in certain circumstances (an 'advance refusal'), and those circumstances arise, you must abide by that refusal.

This summary cannot cover all situations. For more detail, consult the *Reference guide to consent for examination or treatment*, available from the NHS Response Line 08701 555 455 and at [www.doh.gov.uk/](http://www.doh.gov.uk/).

**Consent Form 1****Patient agreement to  
investigation or treatment**

*Afix Patient Label here*

**Name of proposed procedure or course of treatment**

(include brief explanation if medical term not clear)

**Statement of health professional**

I have explained the procedure to the patient. In particular, I have explained:

The intended benefits:

Serious or frequently occurring risks:

Any extra procedures which may become necessary during the procedure:

I have also discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

This procedure will involve:

local anesthesia

Clinician's signature: _____	Date: _____
Name (PRINT): _____	Job Title: _____
<b>Statement of patient</b>	
Please read this form carefully. If you have any further questions, please ask – we are here to help you. You have the right to change your mind at any time, including after you have signed this form up to the point of commencement of your procedure.	
<b>I agree</b> to the procedure or course of treatment described on this form.	
<b>I understand</b> that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or prevent serious harm to my health.	
Patient's signature: _____	Date: _____
Name (PRINT): _____	Job title: _____
<b>A witness should sign below if the patient is unable to sign but has indicated his or her consent.</b>	
<b>Young people/children may also like a parent to sign here (see notes).</b>	
Patient's signature: _____	Date: _____
Name (PRINT): _____	
<b>Important Note</b>	
<input type="checkbox"/> Patient has withdrawn consent	
(Tick & Patient to sign here) _____	

### Guidance to health professionals (to be read in conjunction with consent policy)

#### What this consent form is for

This form documents the patient's agreement to go ahead with the investigation or treatment you have proposed. It is not a legal waiver – if patients, for example, do not receive enough information on which to base their decision, then the consent may not be valid, even though the form has been signed. Patients are also entitled to change their mind after signing the form, if they retain capacity to do so. The form should act as an aide-memoire to health professionals and patients, by providing a check-list of the kind of information patients should be offered, and by enabling the patient to have a written record of the main points discussed. In no way, however, should the written information provided for the patient be regarded as a substitute for face-to-face discussions with the patient.

#### The law on consent

See the Department of Health's *Reference guide to consent for examination or treatment* for a comprehensive summary of the law on consent (also available at [www.doh.gov.uk/](http://www.doh.gov.uk/)).

#### Who can give consent

Everyone aged 16 or more is presumed to be competent to give consent for themselves, unless the opposite is demonstrated. If a child under the age of 16 has "sufficient understanding and intelligence to enable him or her to understand fully what is proposed", then he or she will be competent to give consent for himself or herself. Young people aged 16 and 17, and legally 'competent' younger children, may therefore sign this form for themselves, but may like a parent to countersign as well. If the child is not able to give consent for himself or herself, some-one with parental responsibility may do so on their behalf and a separate form is available for this purpose. Even where a child is able to give consent for himself or herself, you should always involve those with parental responsibility in the child's care, unless the child specifically asks you not to do so. If a patient is mentally competent to give consent but is physically unable to sign a form, you should complete this form as usual, and ask an independent witness to confirm that the patient has given consent orally or non-verbally.

### **When NOT to use this form**

If the patient is 18 or over and is not legally competent to give consent, you should use form 4 (form for adults who are unable to consent to investigation or treatment) instead of this form. A patient will not be legally competent to give consent if:

- they are unable to comprehend and retain information material to the decision and/or
- they are unable to weigh and use this information in coming to a decision.

You should always take all reasonable steps (for example involving more specialist colleagues) to support a patient in making their own decision, before concluding that they are unable to do so. Relatives **cannot** be asked to sign this form on behalf of an adult who is not legally competent to consent for himself or herself.

### **Information**

Information about what the treatment will involve, its benefits and risks (including side-effects and complications) and the alternatives to the particular procedure proposed, is crucial for patients when making up their minds. The courts have stated that patients should be told about 'significant risks which would affect the judgment of a reasonable patient'. 'Significant' has not been legally defined, but the GMC requires doctors to tell patients about 'serious or frequently occurring' risks. In addition if patients make clear they have particular concerns about certain kinds of risk, you should make sure they are informed about these risks, even if they are very small or rare. You should always answer questions honestly. Sometimes, patients may make it clear that they do not want to have any information about the options, but want you to decide on their behalf. In such circumstances, you should do your best to ensure that the patient receives at least very basic information about what is proposed. Where information is refused, you should document this on page 2 of the form or in the patient's notes.

## Consent Form 2

### Parental agreement to investigation or treatment for a child or young person



*Afix Patient Label here*

**Name of proposed procedure or course of treatment**

(include brief explanation if medical term not clear)

**Statement of health professional**

I have explained the procedure to the patient. In particular, I have explained:

The intended benefits:

Serious or frequently occurring risks:

Any extra procedures which may become necessary during the procedure:

I have also discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient and his or her parents.

This procedure will involve:

local anesthesia

Clinician's  
signature:

Date:

Name (PRINT): _____	Job title: _____
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### Statement of parent

Please read this form carefully. If you have any further questions, please ask – we are here to help you and your child. You have the right to change your mind at any time, including after you have signed this form up to the point of commencement of your child's procedure.

**I agree** to the procedure or course of treatment described on this form and **I confirm** that I have 'parental responsibility' for this child.

**I understand** that any procedure in addition to those described on this form will only be carried out if it is necessary to save the life of my child or to prevent serious harm to his or her health.

**I have been told** about additional procedures which may become necessary during my child's treatment.

Parent's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name (PRINT): \_\_\_\_\_ Relationship to Child: \_\_\_\_\_

### Child's agreement to treatment (if child wishes to sign)

I agree to have the treatment I have been told about.

Name (PRINT): \_\_\_\_\_ Child's signature: \_\_\_\_\_

Date: \_\_\_\_\_

### Important Note

Parent has withdrawn consent

(Tick & Parent to sign here) \_\_\_\_\_

## Guidance to health professionals

### This form

This form should be used to document consent to a child's treatment, where that consent is being given by a person with parental responsibility for the child. The term 'parent' has been used in this form as a shorthand for 'person with parental responsibility'. Where children are legally competent to consent for themselves (see below), they may sign the standard 'adult' consent form (form 1). There is space on that form for a parent to countersign if a competent child wishes them to do so.

### Who can give consent?

Everyone aged 16 or more is presumed to be competent to give consent for themselves, unless the opposite is demonstrated. The courts have stated that if a child under the age of 16 has "sufficient understanding and intelligence to enable him or her to understand fully what is proposed", then he or she will be competent to give consent for himself or herself. If children are not able to give consent for themselves, some-one with parental responsibility may do so on their behalf.

Although children acquire rights to give consent for themselves as they grow older, people with 'parental responsibility' for a child retain the right to give consent on the child's behalf until the child reaches the age of 18. Therefore, for a number of years, both the child and a person with parental responsibility have the right to give consent to the child's treatment. In law, health professionals only need the consent of one appropriate person before providing treatment. This means that in theory it is lawful to provide treatment to a child under 18 which a person with parental responsibility has authorised, even if the child refuses. As a matter of good practice, however, you should always seek a competent child's consent before providing treatment unless any delay involved in doing so would put the child's life or health at risk. Younger children should also be as involved as possible in decisions about their healthcare. Further advice is given in the Department's guidance *Seeking consent: working with children*. Any differences of opinion between the child and their parents, or between parents, should be clearly documented in the patient's notes.

### Parental responsibility

The person(s) with parental responsibility will usually, but not invariably, be the child's birth parents. People with parental responsibility for a child include: the child's mother; the child's father if married to the mother at the child's conception, birth or later; a legally appointed guardian; the local authority if the child is on a care order; or a person named in a residence order in respect of the child. Fathers who have never been married to the child's mother will only have parental responsibility if they have acquired it through a court order or parental responsibility agreement (although this may change in the future).

### Information

Information about what the treatment will involve, its benefits and risks (including side-effects and complications) and the alternatives to the particular procedure proposed, is crucial for children and their parents when making up their minds about treatment. The courts have stated that patients should be told about 'significant risks which would affect the judgment of a reasonable patient'. 'Significant' has not been legally defined, but the GMC requires doctors to tell patients about 'serious or frequently occurring' risks. In addition if patients make clear they have particular concerns about certain kinds of risk, you should make sure they are informed about these risks, even if they are very small or rare. You should always answer questions honestly.

### Guidance on the law on consent

See the Department of Health publications *Reference guide to consent for examination or treatment* and *Seeking consent: working with children* for a comprehensive summary of the law on consent, also available at [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_103653.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103653.pdf).

## Consent form 4

### Form for adults who are unable to consent to investigation or treatment

*pre-printed label  
here*

#### All sections to be completed by health professional proposing the procedure

##### A Details of procedure or course of treatment proposed

##### B Assessment of patient's capacity

I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because:

- the patient is unable to comprehend and retain information material to the decision; and/or
- the patient is unable to use and weigh this information in the decision-making process; or
- the patient is unconscious

Further details (excluding where patient unconscious): for example how above judgments reached; which colleagues consulted; what attempts made to assist the patient make his or her own decision and why these were not successful.

##### C Assessment of patient's best interests

To the best of my knowledge, the patient has not refused this procedure in a valid advance directive. Where possible and appropriate, I have consulted with colleagues and those close to the patient and I believe the procedure to be in the patient's best interests because:

(Where incapacity is likely to be temporary, for example if patient unconscious, or where patient has fluctuating capacity)

The treatment cannot wait until the patient recovers capacity because:

## D Involvement of the patient's family and others close to the patient

The final responsibility for determining whether a procedure is in an incapacitated patient's best interests lies with the health professional performing the procedure. However, it is good practice to consult with those close to the patient (eg spouse/partner, family and friends, carer, supporter or advocate) unless you have good reason to believe that the patient would not have wished particular individuals to be consulted, or unless the urgency of their situation prevents this. "Best interests" go far wider than "best medical interests" and include factors such as the patient's wishes and beliefs when competent, their current wishes, their general well-being and their spiritual and religious welfare. (to be signed by a person or persons close to the patient, if they wish)

**I/We have been involved in a discussion with the relevant health professionals over the treatment of (patient's name). I/We understand that he/she is unable to give his/her own consent, based on the criteria set out in this form. I/We also understand that treatment can lawfully be provided if it is in his/her best interests to receive it.**

Any other comments (including any concerns about decision)

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name (PRINT): \_\_\_\_\_

Relationship  
to Patient: \_\_\_\_\_

Signatories Address (if not the same as patient):

If a person close to the patient was not available in person, has this matter been discussed in any other way (eg over the telephone?)

Yes  No

**Details:**

## Signature of health professional proposing treatment

The above procedure is, in my clinical judgment, in the best interests of the patient, who lacks capacity to consent for himself or herself. Where possible and appropriate I have discussed the patient's condition with those close to him or her, and taken their knowledge of the patient's views and beliefs into account in determining his or her best interests.

I have/have\* not sought a second opinion.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name (PRINT): _____	Job title: _____
<b>Where second opinion sought, s/he should sign below to confirm agreement:</b>	
Signature: _____	Date: _____
Name (PRINT): _____	Job title: _____

## **Guidance to health professionals** (to be read in conjunction with consent policy)

This form should only be used where it would be usual to seek written consent but an adult patient (18 or over) lacks capacity to give or withhold consent to treatment. If an adult **has** capacity to accept or refuse treatment, you should use the standard consent form and respect any refusal. Where treatment is very urgent (for example if the patient is critically ill), it may not be feasible to fill in a form at the time, but you should document your clinical decisions appropriately afterwards. If treatment is being provided under the authority of Part IV of the *Mental Health Act 1983*, different legal provisions apply and you are required to fill in more specialised forms (although in some circumstances you may find it helpful to use this form as well). If the adult now lacks capacity, but has clearly refused particular treatment in advance of their loss of capacity (for example in an advance directive or 'living will'), then you must abide by that refusal if it was validly made and is applicable to the circumstances. For further information on the law on consent, see the Department of Health's *Reference guide to consent for examination or treatment* ([www.doh.gov.uk/consent](http://www.doh.gov.uk/consent)).

### **When treatment can be given to a patient who is unable to consent**

For treatment to be given to a patient who is unable to consent, the following **must** apply:

- the patient must lack the capacity ('competence') to give or withhold consent to this procedure AND
- the procedure must be in the patient's best interests.

### **Capacity**

A patient will lack capacity to consent to a particular intervention if he or she is:

- unable to comprehend and retain information material to the decision, especially as to the consequences of having, or not having, the intervention in question; and/or
- unable to use and weigh this information in the decision-making process.

Before making a judgment that a patient lacks capacity you must take all steps reasonable in the circumstances to assist the patient in taking their own decisions (this will clearly not apply if the patient is unconscious). This may involve explaining what is involved in very simple language, using pictures and communication and decision-aids as appropriate. People close to the patient (spouse/partner, family, friends and carers) may often be able to help, as may specialist colleagues such as speech and language therapists or learning disability teams, and independent advocates or supporters. Capacity is 'decision-specific': a patient may lack capacity to take a particular complex decision, but be quite able to take other more straight-forward decisions or parts of decisions.

### **Best interests**

A patient's best interests are not limited to their best medical interests. Other factors which form part of the best interests decision include:

- the wishes and beliefs of the patient when competent
- their current wishes
- their general well-being
- their spiritual and religious welfare

Two incapacitated patients, whose *physical* condition is identical, may therefore have different best interests. Unless the patient has clearly indicated that particular individuals should not be involved in their care, or unless the urgency of their situation prevents it, you should attempt to involve people close to the patient (spouse/partner, family and friends, carer, supporter or advocate) in the decision-making process. Those close to the patient cannot require you to provide particular treatment which you do not believe to be clinically appropriate. However they will know the patient much better than you do, and therefore are likely to be able to provide valuable information about the patient's wishes and values.

### **Second opinions and court involvement**

Where treatment is complex and/or people close to the patient express doubts about the proposed treatment, a second opinion should be sought, unless the urgency of the patient's condition prevents this. Donation of regenerative tissue such as bone marrow, sterilisation for contraceptive purposes and withdrawal of artificial nutrition or hydration from a patient in PVS must never be undertaken without prior High Court approval. High Court approval can also be sought where there are doubts about the patient's capacity or best interests.

## Information for Patients about Consent

### About the consent form

Before a doctor or other health professional examines or treats you, they need your consent. Sometimes you can simply tell them whether you agree with their suggestions. However, sometimes a written record of your decision is helpful – for example if your treatment involves sedation or general anesthesia. You'll then be asked to sign a consent form. If you later change your mind, you're entitled to withdraw consent – even after signing.

### What should I know before deciding?

Health professionals must ensure you know enough to enable you to decide about treatment. They'll write information on the consent form and offer you a copy to keep as well as discussing the choices of treatment with you. Although they may well recommend a particular option, you're free to choose another. People's attitudes vary on things like the amount of risk or pain they're prepared to accept. That goes for the amount of information, too. If you'd rather not know about certain aspects, discuss your worries with whoever is treating you.

### Should I ask questions?

Always ask anything you want. As a reminder, you can write your questions in the space over the page. The person you ask should do his or her best to answer, but if they don't know they should find some-one else who is able to discuss your concerns. To support you and prompt questions, you might like to bring a friend or relative. Ask if you'd like someone independent to speak up for you.

### Is there anything I should tell people?

If there's any procedure you **don't** want to happen, you should tell the people treating you. It's also important for them to know about any illnesses or allergies which you may have or have suffered from in the past.

### About the consent form

#### Can I find out more about giving consent?

The Department of Health leaflet *Consent – what you have a right to expect* is a detailed guide on consent in versions for adults, children, parents, carers/relatives and people with learning disabilities. Ask for one from your clinic or hospital, order one from the NHS Responseline (08701 555 455) or read it on the web site [www.doh.gov.uk/](http://www.doh.gov.uk/).

#### Who is treating me?

Amongst the health professionals treating you may be a "doctor in training" – medically qualified, but now doing more specialist training. They range from recently qualified doctors to doctors almost ready to be consultants. They will only carry out procedures for which they have been appropriately trained. Someone senior will supervise – either in person accompanying a less experienced doctor in training or available to advise someone more experienced.

#### Will samples be taken?

Some kinds of operation involve removing a part of the body (such as a skin tissue). You would always be told about this in advance. Other operations may mean taking samples as part of your care. These samples may be of blood or small sections of tissue, for example of an unexplained lump. Such samples may be further checked by other health professionals to ensure the best possible standards. Again, you should be told in advance if samples are likely to be taken. Sometimes samples taken during operations may also be used for teaching, research or public health monitoring in the future interests of all NHS patients. The NHS trust treating you will have a local system for checking whether you're willing for this to happen.

### **Photographs and videos**

As part of your treatment some kind of photographic record may be made – for example X-rays, clinical photographs or sometimes a video. You will always be told if this is going to happen. The photograph or recording will be kept with your notes and will be held in confidence as part of your medical record. This means that it will normally be seen only by those involved in providing you with care or those who need to check the quality of care you have received. The use of photographs and recordings is also extremely important for other NHS work, such as teaching or medical research. However, we will not use yours in a way that might allow you to be identified or recognised without your express permission.

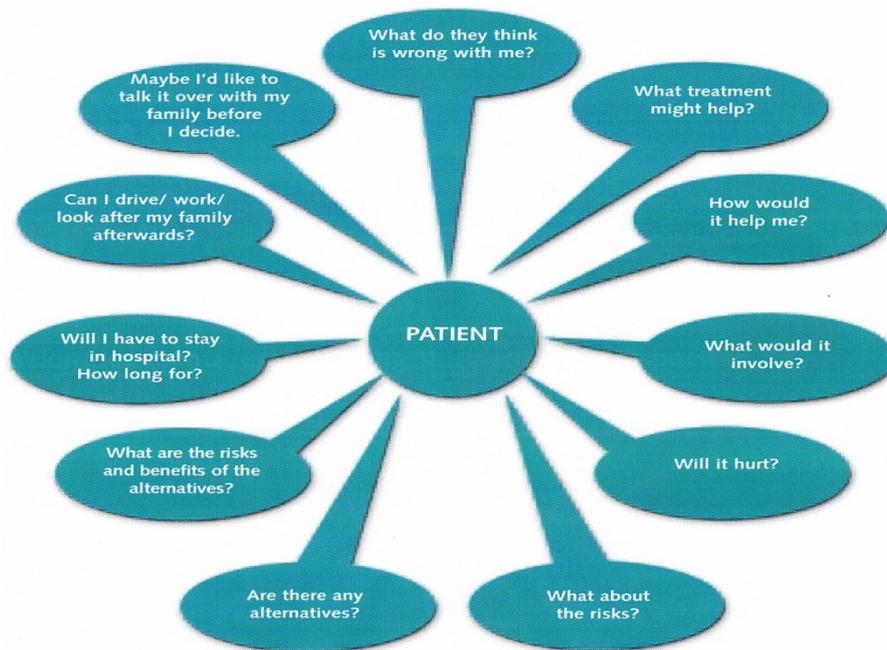
### **What if things don't go as expected?**

Amongst the 25,000 operations taking place every day, sometimes things don't go as they should. Although the doctor involved should inform you and your family, often the patient is the first to notice something amiss. If you're worried – for example about the after-effects of an operation continuing much longer than you were told to expect – tell a health professional right away. Speak to your GP, or contact your clinic - the phone number should be on your appointment card, letter or consent form copy.

### **What are the key things to remember?**

It's your decision! It's up to you to choose whether or not to consent to what's being proposed. Ask as many questions as you like, and remember to tell the team about anything that concerns you or about any medication, allergies or past history which might affect your general health.

## **Questions to ask health professionals**



As well as giving you information health professionals must listen and do their best to answer your questions. Before your next appointment, you can write some down in the space below.

Questions may be about the **treatment itself**, for example:

- What are the main treatment options?
- What are the benefits of each of the options?
- What are the risks, if any, of each option?
- What are the success rates for different options – nationally, for this unit or for you (the surgeon)?
- Why do you think an operation (if suggested) is necessary?
- What are the risks if I decide to do nothing for the time being?
- How can I expect to feel after the procedure?
- When am I likely to be able to get back to work?

Questions may also be about how the treatment might affect your future state of health or style of life, for example:

- Will I need long-term care?
- Will my mobility be affected?
- Will I still be able to drive?
- Will it affect the kind of work I do?
- Will it affect my personal/sexual relationships?
- Will I be able to take part in my favourite sport/exercises?
- Will I be able to follow my usual diet?

Health care professionals should welcome your views and discuss any issues so they can work in partnership with you for the best outcome.





# Consent: patients and doctors making decisions together

General  
Medical  
Council

Regulating doctors  
Ensuring good medical practice

# Consent: patients and doctors making decisions together

Guidance for doctors

(All GMC guidance can be found on their website at [www.gmc-uk.org/guidance](http://www.gmc-uk.org/guidance))

## The duties of a doctor registered with the General Medical Council

This guidance came into effect on 2 June 2008

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.

## Consent: patients and doctors making decisions together

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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 judgment 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.
- 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 judgment, 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.

- (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.
- 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.

## 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 benefit
  - (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. 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 appropriate
  - (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*.<sup>7</sup>

#### 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.
- 32 You must tell patients if an investigation or treatment might result in a serious adverse outcome,<sup>9</sup> 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.

### 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. 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.<sup>11</sup> 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.<sup>12</sup> 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. There is more information about legislation and case law in the legal annex to this guidance.
- 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 decision<sup>15</sup>
- (e) the views of anyone the patient asks you to consult, or who has legal authority to make a decision on their behalf,<sup>16</sup> or has been appointed to represent them
- (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 interests
- (g) what you and the rest of the healthcare team know about the patient's wishes, feelings, beliefs and values.

- 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.
- 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 setting<sup>20</sup> 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 Broad moor 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* judgment.

- 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 practicing 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.legislation.gov.uk/ukpga/2005/9/contents](http://www.legislation.gov.uk/ukpga/2005/9/contents)

*Mental Capacity Act Code of Practice*  
[www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingdecisionsforsomeoneelse/DG\\_186479](http://www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingdecisionsforsomeoneelse/DG_186479)

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.legislation.gov.uk/asp/2000/4/contents](http://www.legislation.gov.uk/asp/2000/4/contents)

*Scottish Government site for the Act*  
[www.scotland.gov.uk/Topics/Justice/Civil/awi](http://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.dhsspsni.gov.uk/bamford](http://www.dhsspsni.gov.uk/bamford)

*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](http://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.legislation.gov.uk/ukpga/2007/12/contents](http://www.legislation.gov.uk/ukpga/2007/12/contents)

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.legislation.gov.uk/asp/2003/13/contents](http://www.legislation.gov.uk/asp/2003/13/contents)

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.legislation.gov.uk/nisi/1986/595/contents](http://www.legislation.gov.uk/nisi/1986/595/contents)

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.

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.legislation.gov.uk/ukpga/2004/30/contents](http://www.legislation.gov.uk/ukpga/2004/30/contents)

Human Tissue Authority website - Codes of Practice

[www.hta.gov.uk/guidance/codes\\_of\\_practice.cfm](http://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.legislation.gov.uk/asp/2006/4/contents](http://www.legislation.gov.uk/asp/2006/4/contents)

## 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.legislation.gov.uk/ukpga/1990/37/contents](http://www.legislation.gov.uk/ukpga/1990/37/contents)

*Human Fertilisation and Embryology Act 2008*  
[www.legislation.gov.uk/ukpga/2008/22/contents](http://www.legislation.gov.uk/ukpga/2008/22/contents)

Human Fertilisation and Embryology Authority website  
[www.hfea.gov.uk](http://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/guidance/freedom-and-rights/human-rights.htm](http://www.justice.gov.uk/guidance/freedom-and-rights/human-rights.htm)

## Other sources of information and 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*

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# 0-18 years: guidance for all doctors

General  
Medical  
Council

Regulating doctors  
Ensuring good medical practice

# 0–18 years: guidance for all doctors

## 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.

Our booklet *Good Medical Practice* describes what is expected of all doctors registered with the GMC. The guidance that follows, which is for all doctors, develops the duties and principles set out in *Good Medical Practice* and in our other guidance. It focuses on children and young people from birth until their 18th birthday (see appendix 1).

It is your responsibility to be familiar with *Good Medical Practice* and *0-18 years* and to follow the guidance they contain. It is guidance, not a statutory code, so you must use your judgment to apply the principles to the various situations you will face as a doctor, whether or not you hold a licence to practice and whether or not you routinely see patients. You must be prepared to explain and justify your decisions and actions.

In 0–18 years: guidance for all doctors, 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.

Serious or persistent failure to follow this guidance will put your registration at risk.

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## Introduction

- 1 This guidance is for all doctors, but it may also be useful for children, young people\*, those with an interest in their care, and anyone else who wants to know what guidance doctors are given. \* See Appendix 1 for who we mean by children and young people and Appendix 2 for guidance on who has parental responsibility and roles of parents and carers.
- 2 The guidance is for all doctors, whether or not they routinely see children and young people as patients. Doctors should also be aware of the needs and welfare of children and young people when they see patients:
  - (a) who are parents or carers\*
  - (b) who are cared for by children or young people, or
  - (c) who may represent a danger to children or young people.
- 3 *Good Medical Practice* states that doctors must safeguard and protect the health and well-being of children and young people. Well-being includes treating children and young people as individuals and respecting their views, as well as considering their physical and emotional welfare.
- 4 When treating children and young people, doctors must also consider parents and others close to them; but their patient must be the doctor's first concern.
- 5 When treating adults who care for, or pose risks to, children and young people, the adult patient must be the doctor's first concern; but doctors must also consider and act in the best interests of children and young people.

- 6 Children and young people may be particularly vulnerable and need to be protected from harm; they can often find it difficult accessing services or defending their rights; and they often rely on others for their well-being. They may have particular communication needs and may need help to make decisions.
- 7 Children and young people are individuals with rights that should be respected. This means listening to them and taking into account what they have to say about things that affect them. It also means respecting their decisions and confidentiality.
- 8 Doctors should always act in the best interests of children and young people. This should be the guiding principle in all decisions which may affect them. But identifying their best interests is not always easy. This is particularly the case in relation to treatment that does not have proven health benefits or when competent young people refuse treatment that is clearly in their medical interests. There can also be a conflict between child protection and confidentiality, both of which are vitally important to the welfare of children and young people.
- 9 Reaching satisfactory answers to these challenging questions may mean considering a number of difficult ethical and legal issues. The purpose of this guidance is to help doctors balance competing interests and make decisions that are ethical, lawful and for the good of children and young people.
- 10 The law relating to children and young people is complex and differs across the UK. Doctors who have children and young people as patients will need some understanding of the law as it applies where they practice. Summaries of the law contained in this guidance cannot be a substitute for up-to-date legal advice in individual cases.
- 11 When in doubt as to their responsibilities, doctors should seek the advice of experienced colleagues, named or designated doctors for child protection, or professional or regulatory bodies.

## Assessing best interests

- 12 An assessment of best interests will include what is clinically indicated in a particular case. You should also consider:
  - (a) the views of the child or young person, so far as they can express them, including any previously expressed preferences
  - (b) the views of parents
  - (c) the views of others close to the child or young person
  - (d) the cultural, religious or other beliefs and values of the child or parents
  - (e) the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
  - (f) which choice, if there is more than one, will least restrict the child or young person's future options.
- 13 This list is not exhaustive. The weight you attach to each point will depend on the circumstances, and you should consider any other relevant information. You should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability.

## Communication

- 14 Effective communication between doctors and children and young people is essential to the provision of good care. You should find out what children, young people and their parents want and need to know, what issues are important to them, and what opinions or fears they have about their health or treatment. In particular you should:
  - (a) involve children and young people in discussions about their care
  - (b) be honest and open with them and their parents, while respecting confidentiality
  - (c) listen to and respect their views about their health, and respond to their concerns and preferences

- (d) explain things using language or other forms of communication they can understand
  - (e) consider how you and they use non-verbal communication, and the surroundings in which you meet them
  - (f) give them opportunities to ask questions, and answer these honestly and to the best of your ability
  - (g) do all you can to make open and truthful discussion possible, taking into account that this can be helped or hindered by the involvement of parents or other people
  - (h) give them the same time and respect that you would give to adult patients.
- 15 You should make it clear that you are available to see children and young people on their own if that is what they want. You should avoid giving the impression (whether directly, through reception staff or in any other way) that they cannot access services without a parent. You should think carefully about the effect the presence of a chaperone<sub>s</sub> can have. Their presence can deter young people from being frank and from asking for help.
- 16 You should take children and young people's views seriously and not dismiss or appear to dismiss their concerns or contributions. Disabled children and young people can feel particularly disadvantaged in this respect.
- 17 Children and young people usually want or need to know about their illnesses and what is likely to happen to them in the future. You should provide information that is easy to understand and appropriate to their age and maturity about:
- (a) their conditions
  - (b) the purpose of investigations and treatments you propose and what that involves, including pain, anaesthetics and stays in hospital
  - (c) the chances of success and the risks of different treatment options, including not having treatment
  - (d) who will be mainly responsible for and involved in their care
  - (e) their right to change their minds or to ask for a second opinion.
- 18 You should not overburden children and young people or their parents, but give them information at an appropriate time and pace, and check their understanding of key points.
- 19 You should talk directly and listen to children and young people who are able to take part in discussions about their care. Young people who are able to understand what is being said and who can speak for themselves resent being spoken about when they are present. But younger children might not be able to understand what their illness or proposed treatment is likely to involve, even when explained in straightforward terms.
- 20 You should only keep the type of information described in paragraph 17 from children or young people if:
- (a) it would cause them serious harm (and not just upset them or make them more likely to want to refuse treatment)
  - (b) they ask you to, because they would prefer someone else to make decisions for them.
- 21 You have the same duty of confidentiality to children and young people as you have to adults. But parents often want and need information about their children's care so that they can make decisions or provide care and support. Children and young people are usually happy for information to be shared with their parents. This sharing of information is often in the best interests of children and young people, particularly if their health would benefit from special care or ongoing treatment, such as a special diet or regular medication. Parents are usually the best judges of their children's best interests and should make important decisions up until children are able to make their own decisions. You should share relevant information with parents in accordance with the law and the guidance in paragraphs 27, 28 and 42 to 55.

## Making decisions

- 22 You can provide medical treatment to a child or young person with their consent if they are competent to give it, or with the consent of a parent or the court.<sup>4</sup> You can provide emergency treatment without consent to save the life of, or prevent serious deterioration in the health of, a child or young person.
- 23 You should involve children and young people as much as possible in decisions about their care, even when they are not able to make decisions on their own.

### Assessing the capacity to consent

- 24 You must decide whether a young person is able to understand the nature, purpose and possible consequences of investigations or treatments you propose, as well as the consequences of not having treatment. Only if they are able to understand, retain, use and weigh this information, and communicate their decision to others can they consent to that investigation or treatment.<sup>5</sup> That means you must make sure that all relevant information has been provided and thoroughly discussed before deciding whether or not a child or young person has the capacity to consent.
- 25 The capacity to consent depends more on young people's ability to understand and weigh up options than on age. When assessing a young person's capacity to consent, you should bear in mind that:
- (a) at 16 a young person can be presumed to have the capacity to consent (see paragraphs 30 to 33)
  - (b) a young person under 16 may have the capacity to consent, depending on their maturity and ability to understand what is involved.
- 26 It is important that you assess maturity and understanding on an individual basis and with regard to the complexity and importance of the decision to be made. You should remember that a young person who has the capacity to consent to straightforward, relatively risk-free treatment may not necessarily have the capacity to consent to complex treatment involving high risks or serious consequences.\* The capacity to consent can also be affected by their physical and emotional development and by changes in their health and treatment. \* See paragraphs 70–71 for guidance on advice and treatment for contraception, abortion and sexually transmitted infections.

#### Children and young people who lack the capacity to consent

- 27 If a child lacks the capacity to consent, you should ask for their parent's consent. It is usually sufficient to have consent from one parent. If parents cannot agree and disputes cannot be resolved informally, you should seek legal advice about whether you should apply to the court.
- 28 The legal framework for the treatment of 16- and 17-year-olds who lack the capacity to consent differs across the UK:
- (a) In England, Wales and Northern Ireland, parents can consent to investigations and treatment that are in the young person's best interests
  - (b) In England and Wales, treatment can also be provided in the young person's best interests without parental consent, although the views of parents may be important in assessing the young person's best interests (see paragraphs 12 and 13)
  - (c) In Northern Ireland, treatment can be provided in the young person's best interests if a parent cannot be contacted, although you should seek legal advice about applying for court approval for significant (other than emergency) interventions
  - (d) In Scotland, 16- and 17-year-olds who do not have the capacity to consent are treated as adults who lack capacity and treatment may be given to safeguard or promote their health.

#### Young people who have the capacity to consent

- 29 You should encourage young people to involve their parents in making important decisions, but you should usually abide by any decision they have the capacity to make themselves (see paragraphs 30 to 33 and paragraphs 46 to 52). You should also consider involving other members of the multi-disciplinary team, an independent advocate or a named or designated doctor for child protection if their involvement would help young people in making decisions.

### If a young person refuses treatment

- 30 Respect for young people's views is important in making decisions about their care. If they refuse treatment, particularly treatment that could save their life or prevent serious deterioration in their health, this presents a challenge that you need to consider carefully.

- 31 Parents cannot override the competent consent of a young person to treatment that you consider is in their best interests. But you can rely on parental consent when a child lacks the capacity to consent. In Scotland parents cannot authorise treatment a competent young person has refused. In England, Wales and Northern Ireland, the law on parents overriding young people's competent refusal is complex. You should seek legal advice if you think treatment is in the best interests of a competent young person who refuses.
- 32 You must carefully weigh up the harm to the rights of children and young people of overriding their refusal against the benefits of treatment, so that decisions can be taken in their best interests.<sup>13</sup> In these circumstances, you should consider involving other members of the multi-disciplinary team, an independent advocate, or a named or designated doctor for child protection. Legal advice may be helpful in deciding whether you should apply to the court to resolve disputes about best interests that cannot be resolved informally.
- 33 You should also consider involving these same colleagues before seeking legal advice if parents refuse treatment that is clearly in the best interests of a child or young person who lacks capacity, or if both a young person with capacity and their parents refuse such treatment. For further guidance on these issues see GMC guidance on consent and treatment and care towards the end of life.

### **Procedures undertaken mainly for religious, cultural, social or emotional reasons**

- 34 Both the GMC and the law permit doctors to undertake procedures that do not offer immediate or obvious therapeutic benefits for children or young people, so long as they are in their best interests (see paragraphs 12 and 13) and performed with consent (see paragraph 27).
- 35 To assess their best interests you should consider the religious and cultural beliefs and values of the child or young person and their parents as well as any social, psychological and emotional benefits. This may be relevant in circumcision of male children for religious or cultural reasons<sup>15</sup>, or surgical correction of physical characteristics that do not endanger the child's life or health.

### **Research**

- 36 Research<sup>16</sup> involving children and young people can benefit all children; but they may be vulnerable because they cannot always recognise their best interests, express their needs or defend their rights.
- 37 Children or young people should be involved in research only when research on adults cannot provide the same benefits. They can be involved in research that has either:
- (a) potential benefits for children or young people generally, as long as the research does not go against their best interests or involves only minimal or low risk of harm (this would be research that involves, for example, asking questions or taking blood samples, the assessment of the risk depending on the view of the child or young person), or
  - (b) potential therapeutic benefits for them that outweigh any foreseeable risks, which should be kept as low as possible.
- 38 Children and young people should not usually be involved in research if they object or appear to object in either words or actions, even if their parents consent. If they are able to consent for themselves, you should still consider involving their parents, depending on the nature of the research.
- 39 You must not put pressure on children, young people or their parents to consent to research in the expectation of therapeutic, financial or any other benefit.
- 40 Before involving children or young people in research, you should seek advice and get the necessary approval from a relevant research ethics committee, the Medical Research Council<sup>18</sup> or a medical royal college. For further information see GMC guidance on research.

### **Donation, transplantation, organ and tissue storage and use**

- 41 *The Human Tissue Act 2004 and Human Tissue (Scotland) Act 2006* were passed following inquiries into the storage of children's organs and tissue without the proper consent. The Acts make consent central to the lawful storage and use of children and young people's organs and tissue, and to the removal of such material after death. The Human Tissue Authority regulates and issues codes of practice on activities covered by the Act in England, Wales and Northern Ireland. Scottish ministers have those powers in Scotland.

## Principles of confidentiality

- 42 Respecting patient confidentiality is an essential part of good care; this applies when the patient is a child or young person as well as when the patient is an adult. Without the trust that confidentiality brings, children and young people might not seek medical care and advice, or they might not tell you all the facts needed to provide good care.
- 43 The same duties of confidentiality apply when using, sharing or disclosing information about children and young people as about adults. You should:
- disclose information that identifies the patient only if this is necessary to achieve the purpose of the disclosure – in all other cases you should anonymise<sup>20</sup> the information before disclosing it
  - inform the patient\* about the possible uses of their information, including how it could be used to provide their care and for clinical audit. \* or, where appropriate, those with parental responsibility for the patient
  - ask for the patient's\* consent before disclosing information that could identify them, if the information is needed for any other purpose, other than in the exceptional circumstances described in this guidance
  - keep disclosures to the minimum necessary.

For further information see GMC guidance on confidentiality.

### Sharing information with the consent of the child or young person

- 44 Sharing information with the right people can help to protect children and young people from harm and ensure that they get the help they need. It can also reduce the number of times they are asked the same questions by different professionals. By asking for their consent to share relevant information, you are showing them respect and involving them in decisions about their care.
- 45 If children and young people are able to take part in decision-making, you should explain why you need to share information, and ask for their consent. They will usually be happy for you to talk to their parents and others involved in their care or treatment.

### Sharing information without consent

- 46 If a child or young person does not agree to disclosure there are still circumstances in which you should disclose information:
- when there is an overriding public interest in the disclosure
  - when you judge that the disclosure is in the best interests of a child or young person who does not have the maturity or understanding to make a decision about disclosure
  - when disclosure is required by law.

#### Public interest

- 47 You can disclose, without consent, information that identifies the child or young person, in the public interest. A disclosure is in the public interest if the benefits which are likely to arise from the release of information outweigh both the child or young person's interest in keeping the information confidential and society's interest in maintaining trust between doctors and patients. You must make this judgment case by case, by weighing up the various interests involved.
- 48 When considering whether disclosure would be justified you should:

- (a) tell the child or young person what you propose to disclose and why, unless that would undermine the purpose or place the child or young person at increased risk of harm
- (b) ask for consent to the disclosure, if you judge the young person to be competent to make the decision, unless it is not practical to do so.

- 49** If a child or young person refuses consent, or if it is not practical to ask for consent, you should consider the benefits and possible harms that may arise from disclosure. You should consider any views given by the child or young person on why you should not disclose the information. But you should disclose information if this is necessary to protect the child or young person, or someone else, from risk of death or serious harm. Such cases may arise, for example, if:
- (a) a child or young person is at risk of neglect or sexual, physical or emotional abuse (see paragraphs 56 to 63)
  - (b) the information would help in the prevention, detection or prosecution of serious crime, usually crime against the person
  - (c) a child or young person is involved in behaviour that might put them or others at risk of serious harm, such as serious addiction, self-harm or joy-riding.
- 50** If you judge that disclosure is justified, you should disclose the information promptly to an appropriate person or authority and record your discussions and reasons. If you judge that disclosure is not justified, you should record your reasons for not disclosing.

#### Disclosures when a child lacks the capacity to consent

- 51** Children will usually be accompanied by parents or other adults involved in their care, and you can usually tell if a child agrees to information being shared by their behaviour. Occasionally, children who lack the capacity to consent will share information with you on the understanding that their parents are not informed. You should usually try to persuade the child to involve a parent in such circumstances. If they refuse and you consider it is necessary in the child's best interests for the information to be shared (for example, to enable a parent to make an important decision, or to provide proper care for the child), you can disclose information to parents or appropriate authorities. You should record your discussions and reasons for sharing the information.

#### Disclosures required by law

- 52** You must disclose information as required by law. You must also disclose information when directed to do so by a court.

## Access to medical records by children, young people and their parents

- 53** Young people with capacity have the legal right to access their own health records and can allow or prevent access by others, including their parents.\* In Scotland, anyone aged 12 or over is legally presumed to have such capacity. A child might of course achieve capacity earlier or later. In any event you should usually let children access their own health records. But they should not be given access to information that would cause them serious harm or any information about another person without the other person's consent. \* There are circumstances in which disclosures may be made to parents and others without consent (see paragraphs 46–52).
- 54** You should let parents access their child's medical records if the child or young person consents, or lacks capacity, and it does not go against the child's best interests. If the records contain information given by the child or young person in confidence you should not normally disclose the information without their consent.
- 55** Divorce or separation does not affect parental responsibility and you should allow both parents reasonable access to their children's health records.

## Child protection

- 56 Doctors play a crucial role in protecting children from abuse and neglect. You may be told or notice things that teachers and social workers, for example, may not. You may have access to confidential information that causes you to have concern for the safety or well-being of children.
- 57 Early identification of risks can help children and young people get the care and support they need to be healthy, safe and happy, and to achieve their potential.
- 58 If you work with children or young people, you should have the knowledge and skills to identify abuse and neglect. You should be aware of the use of frameworks for assessing children and young people's needs, the work of Local Safeguarding Children's Boards and Child Protection Committees, and policies, procedures and organisations that work to protect children and promote their welfare.
- 59 Children, young people and parents may not want you to disclose information about them if they think they will be denied help, blamed or made to feel ashamed. They might have had bad experiences or fear contact with the police or social services. You should help them understand the importance and benefits of sharing information. But you must not delay sharing relevant information with an appropriate person or authority if delay would increase the risk to the child or young person or to other children or young people.
- 60 Confidentiality is important and information sharing should be proportionate to the risk of harm. You may share some limited information, with consent if possible, to decide if there is a risk that would justify further disclosures. A risk might only become apparent when a number of people with niggling concerns share them. If in any doubt about whether to share information, you should seek advice from an experienced colleague, a named or designated doctor for child protection, or a Caldicott Guardian. You can also seek advice from a professional body, defence organisation or the GMC. You will be able to justify raising a concern, even if it turns out to be groundless, if you have done so honestly, promptly, on the basis of reasonable belief, and through the appropriate channels.
- 61 Your first concern must be the safety of children and young people. You must inform an appropriate person or authority promptly of any reasonable concern that children or young people are at risk of abuse or neglect, when that is in a child's best interests or necessary to protect other children or young people. You must be able to justify a decision not to share such a concern, having taken advice from a named or designated doctor for child protection or an experienced colleague, or a defence or professional body. You should record your concerns, discussions and reasons for not sharing information in these circumstances.
- 62 You should participate fully in child protection procedures, attend meetings whenever practical and cooperate with requests for information about child abuse and neglect. This includes Serious Case Reviews set up to identify why a child has been seriously harmed, to learn lessons from mistakes and to improve systems and services for children and their families. When the overall purpose of a review is to protect other children or young people from a risk of serious harm, you should share relevant information, even when a child or young person or their parents do not consent, or if it is not possible to ask for consent. You must be prepared to justify your decision not to share information in such cases.
- 63 You should make sure that there are clear and well-understood policies and procedures for sharing information with agencies you work with closely or often. You should have an understanding of the roles, policies and practices of other agencies and professionals. This includes understanding the circumstances in which they consider disclosure to be justified. Teachers, social workers, police, youth offending teams and others all have different relationships with children and young people. They also have different cultures, policies and guidance on sharing information. You should understand and respect these differences but remember the particular responsibilities you have as a doctor and the importance of trust in your relationship with your patients.

## Sexual activity

- 64 A confidential sexual health service is essential for the welfare of children and young people. Concern about confidentiality is the biggest deterrent to young people asking for sexual health advice. That in turn presents dangers to young people's own health and to that of the community, particularly other young people.

- 65 You can disclose relevant information when this is in the public interest (see paragraphs 47 to 50). If a child or young person is involved in abusive or seriously harmful sexual activity, you must protect them by sharing relevant information with appropriate people or agencies, such as the police or social services, quickly and professionally.
- 66 You should consider each case on its merits and take into account young people's behaviour, living circumstances, maturity, serious learning disabilities, and any other factors that might make them particularly vulnerable.
- 67 You should usually share information about sexual activity involving children under 13, who are considered in law to be unable to consent.<sup>28</sup> You should discuss a decision not to disclose with a named or designated doctor for child protection and record your decision and the reasons for it.
- 68 You should usually share information about abusive or seriously harmful sexual activity involving any child or young person, including that which involves:
- (a) a young person too immature to understand or consent
  - (b) big differences in age, maturity or power between sexual partners
  - (c) a young person's sexual partner having a position of trust
  - (d) force or the threat of force, emotional or psychological pressure, bribery or payment, either to engage in sexual activity or to keep it secret
  - (e) drugs or alcohol used to influence a young person to engage in sexual activity when they otherwise would not
  - (f) a person known to the police or child protection agencies as having had abusive relationships with children or young people.
- 69 You may not be able to judge if a relationship is abusive without knowing the identity of a young person's sexual partner, which the young person might not want to reveal. If you are concerned that a relationship is abusive, you should carefully balance the benefits of knowing a sexual partner's identity against the potential loss of trust in asking for or sharing such information.

## Contraception, abortion and sexually transmitted infections (STIs)

- 70 You can provide contraceptive, abortion<sup>30</sup> and STI advice and treatment, without parental knowledge or consent, to young people under 16 provided that:
- (a) they understand all aspects of the advice and its implications
  - (b) you cannot persuade the young person to tell their parents or to allow you to tell them
  - (c) in relation to contraception and STIs, the young person is very likely to have sex with or without such treatment
  - (d) their physical or mental health is likely to suffer unless they receive such advice or treatment, and
  - (e) it is in the best interests of the young person to receive the advice and treatment without parental knowledge or consent.<sup>31</sup>
- 71 You should keep consultations confidential even if you decide not to provide advice or treatment (for example, if your patient does not understand your advice or the implications of treatment), other than in the exceptional circumstances outlined in paragraphs 46 to 52 and paragraphs 64 to 69.

### Conscientious objections

- 72 If carrying out a particular procedure or giving advice about it conflicts with your religious or moral beliefs, and this conflict might affect the treatment or advice you provide, you must explain this to the patient and tell them they have the right to see another doctor. You should make sure that information about alternative services is readily available to all patients. Children and young people in particular may have difficulty in making alternative arrangements themselves, so you must make sure that

arrangements are made for another suitably qualified colleague to take over your role as quickly as possible.

## Suitability to work with children and young people

- 73 Children are not miniature adults. Good clinical care for children relies on specially trained clinical staff together with equipment, facilities and an environment appropriate to children's needs. If you have children and young people as patients, you should make sure you have the appropriate training and experience in the clinical care of children in your specialty. You should take steps to make sure that, wherever possible, you and members of your team have access to the appropriate premises, equipment and other resources necessary to provide good care. If you also have adults as patients, you should audit separately the care you provide to children and young people.
- 74 If you are responsible for recruiting or employing people, or if you otherwise control who can work with children or young people in your care, you should make sure that their suitability is checked. NHS Employers (part of the NHS Confederation) issues advice on good employment practice, including pre- and post-employment, Criminal Records Bureau, alert notice, vetting and barring scheme and other checks.
- 75 You should follow the GMC's guidance on raising concerns about patient safety if you have concerns that children or young people are, or may be, at risk of harm because of a colleague's conduct, performance or health.

## Complaints

- 76 You should always take children and young people's complaints seriously. You should help them to complain if their rights or interests have been denied or abused, or if they are unhappy with the care they have received or because they have been denied care.

## Prescribing medicines

- 77 If you prescribe medicines for children, you should be familiar with the current guidance published in the British National Formulary for Children.

For further information see GMC guidance on good practice in prescribing medicines.

## Appendix 1

### **Who are children and young people?**

Children and young people are a diverse group with many different needs. This guidance is concerned with children and young people from birth until their 18th birthday. References to 'children' usually mean younger children who lack the maturity and understanding to make important decisions for themselves. Older or more experienced children who can make these decisions are referred to as 'young people'. At 16 it is legally presumed that young people have the ability to make decisions about their own care.

## Appendix 2

### **Parents and parental responsibility**

References to 'parents' in this guidance usually mean those with parental responsibility for the child or young person in question.

Parental responsibility means the rights and responsibilities that parents have in law for their child, including the right to consent to medical treatment for them, up to the age of 18 in England, Wales and Northern Ireland and 16 in Scotland.

Mothers and married fathers have parental responsibility. So do unmarried fathers of children registered since 15 April 2002 in Northern Ireland, since 1 December 2003 in England and Wales and since 4 May 2006 in Scotland, as long as the father is named on the child's birth certificate.

Unmarried fathers whose children's births were registered before these dates, or afterwards if they are not named on the child's birth certificate, do not automatically have parental responsibility. They can acquire parental responsibility by way of a Parental Responsibility Agreement with the child's mother or by getting a Parental Responsibility Order from the courts. Married step-parents and registered civil partners can acquire parental responsibility in the same ways.

Parents do not lose parental responsibility if they divorce. If a child is taken into local authority care parents share parental responsibility with the local authority. Parents lose parental responsibility if a child is adopted. Parental responsibility can be restricted by court order.

Adoptive parents have parental responsibility, as do those appointed as a child's testamentary guardian, special guardian or those given a residence order. Local authorities have parental responsibility while a child is subject to a care order.

You may need to get legal advice when in doubt about who has parental responsibility.

The only parental responsibility that continues until 18 in Scotland is the provision of guidance to the child (see *s.1(1)(b)(ii)* and *s.1(2)(b) Children (Scotland) Act 1995*). The Act refers to parental rights and responsibilities (PRR); reference to parental responsibilities in this guidance means PRR in Scotland.

People without parental responsibility, but who have care of a child, may do what is reasonable in all the circumstances of the case to safeguard or promote the child's welfare. This may include step-parents, grandparents and child minders. You can rely on their consent if they are authorised by the parents. But you should make sure that their decisions are in line with those of the parents, particularly in relation to contentious or important decisions.

## Other sources of information and guidance

*Best Practice Guidance for Doctors and other Health Professionals on the provision of Advice and Treatment to Young People under 16 on Contraception, Sexual and Reproductive Health* (Department of Health, 2004)

*Child protection companion* (Royal College of Paediatrics and Child Health, 2006)

*The Common Assessment Framework for children & young people: Practitioners' and Managers' guides* (both HM Government, 2006)

*Common Core of Skills and Knowledge for the Children's Workforce* (Children's Workforce Development Council, 2010)

*Consent, rights and choices in health care for children and young people* (British Medical Association, 2001)

*Declaration of Helsinki* (World Medical Association, 1964, as amended)

*Delivering a Healthy Future – An Action Framework for Children and Young People's Health in Scotland* (Scottish Executive, 2007)

*Doctors' responsibilities in child protection cases* (British Medical Association, 2004)

*Getting it Right for Every Child* (Scottish Executive, 2006)

*Guidelines for the ethical conduct of medical research involving children* (Royal College of Paediatrics and Child Health: Ethics Advisory Committee in Archives of Disease in Childhood, February 2000, Vol 82, No 2, pp177–182)

*Information sharing: Guidance for practitioners and managers* (HM Government, 2008)

*The law and ethics of male circumcision – Guidance for doctors* (British Medical Association, 2006)

*Medical Research Involving Children* (Medical Research Council, 2004)

*National Service Framework for Children, Young People and Maternity Services* (Department of Health, 2004)

*National Service Framework for Children, Young People and Maternity Services in Wales* (Welsh Assembly Government, 2005)

*NHS Confidentiality Code of Practice* (Department of Health, 2003)

*Safeguarding Children and Young People: Roles and Competences for Health Care Staff* (Royal College of Paediatrics and Child Health, 2006)

*Safeguarding Children: Working Together under the Children Act 2004* (Welsh Assembly Government, 2007)

*Seeking Consent: Working with Children* (Department of Health, 2001)

*Seeking Consent: Working with Children* (Department of Health, Social Services and Public Safety, 2003)

*UN Convention on the Rights of the Child* (United Nations, 1989)

*What to do if you're worried a child is being abused* (Department for Education and Skills, 2006)

*Working together to safeguard children* (Department for children, schools and families, 2010)

*You're Welcome quality criteria: making health services young people friendly* (Department of Health, 2007)

## Legislation and case law

*Adults with Incapacity (Scotland) Act 2000*

*Age of Legal Capacity (Scotland) Act 1991*

*Age of Majority Act 1969, Section 4 (Northern Ireland)*

*Children (Scotland) Act 1995*

*Children Act (Northern Ireland) Order 1995*

*Children Acts 1989 and 2004*

*Family Law Reform Act 1969*

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

*Houston (applicant) [1996] 32 BMLR 93*

*Mental Capacity Act 2005*

*Medicines for Human Use*

*(Clinical Trials) Regulations 2004*

*R (on the application of Sue Axon) v Secretary of State for Health & Anor* [2006] EWHC 37 (Admin), [2006] 1 FCR 175

*Re A (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386

*Re C (Welfare of Child: Immunisation)* [2003] EWCA Civ 1148, [2003] 2 FLR 1095

*Re J (specific issue order: child's religious upbringing and circumcision)* [2000] 1 FLR 571

*Re P (medical treatment: best interests)* [2004] 2 FLR 1117

*Re R (a minor)* [1991] 4 All ER 177

*ReW (A Minor) (Medical Treatment: Court's Jurisdiction)* [1993] Fam 64, [1992] 4 All ER 627 CA

*South Glamorgan County Council vW & B* [1993] 1 FLR 574

## Useful links

### **Charitable umbrella groups**

Children in Northern Ireland – regional umbrella organisation for the children's voluntary sector in Northern Ireland

Children in Scotland – national agency for voluntary, statutory and professional organisations and individuals working with children and their families in Scotland

Children in Wales – national umbrella children's organisation in Wales

National Children's Bureau – umbrella body for organisations working with children and young people in England and Northern Ireland

### **Information and practical resources for children, young people and professionals**

Every Child Matters – information and guidance from the UK Government about its approach to the well-being of children and young people

Health Rights Information Scotland has published guidance specifically for under 16s on consent and confidentiality for the Scottish Executive Health Department

Brook – national voluntary sector provider of free and confidential sexual health advice and services specifically for young people; publishes guidance, leaflets and posters for health professionals, children and young people on a variety of subjects

Connexions – information and advice for young people aged 13–19

### **Legal resources**

Children First for Health – health and hospital web resource providing age-appropriate information for children, young people and their families

The Children's Legal Centre – independent national charity concerned with law and policy affecting children and young people

Scottish Child Law Centre – promotes knowledge and use of Scots law and children's rights for the benefit of children and young people in Scotland

Children's Law Centre (Northern Ireland) – is developing a comprehensive and accessible advice service on children's rights and the law

## **Children's Commissioners**

Children's Commissioners have been appointed for all four home countries. They look after the interests and promote and safeguard the rights of children and young people. Their specific roles and responsibilities vary, but they are important sources of information, advice and advocacy for children and young people.

- Children's Commissioner for England (and non-devolved issues across UK)
- Children's Commissioner for Wales
- Scotland's Commissioner for Children and Young People
- Northern Ireland Commissioner for Children and Young People

### **London**

Regent's Place, 350 Euston Road, London NW1 3JN

### **Manchester**

3 Hardman Street, Manchester M3 3AW

### **Scotland**

5th Floor, The Tun, 4 Jackson's Entry, Holyrood Road, Edinburgh EH8 8PJ

### **Wales**

Regus House, Falcon Drive, Cardiff Bay CF10 4RU

### **Northern Ireland**

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