

BMA

Consent and refusal by adults with decision- making capacity

A toolkit for doctors



British Medical Association
bma.org.uk



Consent and refusal by adults with decision-making capacity – A toolkit for doctors

About this toolkit

- 1: Key questions about consent and refusal
- 2: Capacity to consent
- 3: Sharing information with patients
- 4: Who is responsible for seeking consent?
- 5: Refusal of consent
- 6: Advance care planning
- 7: Consent for emergency treatment
- 8: Compulsory treatment under mental health legislation
- 9: Consent for research
- 10: Consent for teaching purposes
- 11: Further reading

About this toolkit

Consent is required from adult patients with capacity any time a doctor wishes to initiate any examination, treatment or intervention. This toolkit provides practical guidance for doctors about the consent process, and the steps that should be followed in order to obtain valid consent from adult patients. It is designed to answer key questions that doctors may have and includes different sections that relate to specific aspects of consent, such as sharing information with patients, consent in emergency situations and consent for research.

Each section is intended to stand alone, although there are some areas of overlap. The toolkit is not intended to provide definitive guidance on all issues surrounding consent. It is designed to act as a prompt to doctors to aid reflection and decision-making, and to raise awareness of the ethical and legal principles that apply. It includes a section on further reading, with references to other relevant BMA guidance and key external guidance on consent.

This toolkit applies to the UK, and specifies where the law differs in either England, Wales, Scotland or Northern Ireland. It applies only to those over the age of 18. For information on treatment decisions for children and young people (0-18) see our children and young people toolkit which is available at www.bma.org.uk/ethics. It also only applies to adults who have the capacity to give consent. For more information on treating adults who lack capacity, including our toolkit on best interests decision-making see our guidance at www.bma.org.uk/mentalcapacity.



1. Key questions about consent and refusal

Key points

- Consent is required for any examination, treatment or intervention involving an adult who has the capacity to give it, except where compulsory treatment for the patient's psychiatric disorder is authorised under mental health legislation.
- In order for consent to be valid the patient must have capacity, have been offered relevant information, be acting voluntarily and be aware that they can refuse.
- Family members cannot give consent on behalf of an adult who has capacity.
- Consent may be explicit or implied and, except in limited circumstances, need not be in writing.
- Consent is a continuing process, rather than a one-off decision and patients can change their mind about treatment at any time.
- Competent adult patients are entitled to refuse treatment even if that will result in their death or serious harm.
- Patients cannot demand treatment that is not clinically appropriate.

When is it necessary to seek patient consent?

Doctors must obtain consent from patients who have the capacity to give it any time they wish to initiate an examination, treatment or any other intervention. They must also seek consent when involving patients or volunteers in teaching or research (see sections 9 and 10).

The only exceptions to this are in emergencies where it is not possible to obtain consent (see section 7), or when the law prescribes otherwise, such as when compulsory treatment for a patient's psychiatric disorder is authorised by mental health legislation (see section 8). (Mental health legislation cannot authorise non-consensual treatment for physical conditions that are not directly related to a psychiatric disorder.)

Proceeding with treatment without valid consent may put the patient at risk of harm. It also leaves the doctor who is carrying out the procedure and, where different, the doctor who sought consent at risk of criticism and, potentially, legal and/or regulatory sanctions.

What is required for consent to be considered valid?

In order for consent to be valid, patients must:

- have the capacity to make the decision;
- have been offered sufficient information to make an informed decision;
- be acting voluntarily and free from undue pressure; and
- be aware that they can refuse.

Can family members give consent on behalf of an adult patient with capacity?

No. Family members do not have the legal authority to give consent on behalf of an adult patient with capacity. Where the patient has appointed a family member as a health and welfare attorney to make decisions on their behalf (see section 6) this only comes into force when the patient loses capacity.

How should consent be obtained?

Consent can be explicit or implied. Explicit or express consent is when a person actively agrees, either orally or in writing. Implied consent is when consent is signalled by the behaviour of a patient, for example by opening their mouth to allow a doctor to examine their throat. This is not a lesser form of consent, provided the patient genuinely knows and understands what is being proposed and is aware that they have the option to refuse.



Does consent need to be in writing?

Although written consent is only legally required for a small number of treatments (such as some forms of fertility treatment), it is often advised in other circumstances, particularly where the procedure is very invasive or entails more than minimal risks. Doctors should familiarise themselves with the latest clinical guidance in their area of practice. Consent forms can be used to document that discussions about the procedure have taken place. However, consent forms are evidence of the consent process, rather than consent itself; a patient genuinely understanding what is being proposed is more important than how consent is recorded.

What should be recorded in a patient's medical records?

Details of the discussions that have taken place with a patient, and any other relevant people, should be recorded in the patient's medical records. This should usually include discussions about the treatment options, including potential harms and benefits of any treatment, any specific concerns the patient had and any other information that was given to them.

How long is consent valid for?

Consent should be a continuing process, rather than a one-off decision. Patients can change their mind about treatment at any time. Before beginning any treatment, doctors should check that the patient still consents. This is particularly important if a significant length of time has passed since the patient agreed to the treatment; if there is new information available; if there have been any significant changes to the patient's condition; or if the process of seeking consent had been delegated to a colleague. It is important that patients are given continuing opportunities to ask further questions and to review their decisions and are kept informed about the progress of their treatment or care.

Can a competent patient refuse treatment?

Yes. Competent adult patients (those over the age of 18) are entitled to refuse treatment, even if that will result in their death or serious harm (see section 5). The only exception to this is where the law prescribes otherwise, such as when compulsory treatment for the patient's psychiatric disorder is authorised by mental health legislation (see section 8).

Do I have to provide treatment which I do not think is clinically appropriate for the patient?

If a patient asks for treatment that you do not think would be clinically appropriate for them, you should discuss their reasons for requesting it with them. Any significant factors for the patient should be explored further, including non-clinical factors such as their beliefs or views. Following this, if you still consider that the treatment is not clinically appropriate, you do not have to provide it. However, the reasons for this should be explained clearly to the patient, as well as other options available to them, including seeking a second opinion.

What consent should be sought when a health professional has suffered a needlestick injury or other occupational exposure to a patient's blood or bodily fluid?

If they have capacity, consent should be sought from the patient to test them, or an existing sample, for serious communicable diseases. If the patient refuses to consent no test should be carried out. For information on testing of patients who lack capacity in the event of a needlestick injury, see the BMA's separate guidance on needlestick injuries (available at www.bma.org.uk/ethics).

2

2. Capacity to consent

Key points

- People over 16 are presumed to have the capacity to consent to treatment unless there is evidence to the contrary.
- To have capacity to consent an individual must understand, in simple language, what is proposed; understand the benefits, risks and alternatives, and the consequences of not having the treatment; retain the information for long enough to make a decision; and be able to communicate the decision by any means.
- If a patient lacks capacity to consent, treatment decisions must be made following the process set out in the Mental Capacity Act 2005 (England and Wales), Adults with Incapacity (Scotland) Act 2000 or the common law (Northern Ireland).

Are adults presumed to have capacity to consent?

Yes. All people over the age of 16 are presumed, in law, to have the capacity to consent to treatment unless there is evidence to the contrary. You should therefore always begin with the presumption that every adult patient has the capacity to consent to an intervention.

You must not assume that a patient lacks capacity, because they are suffering from a mental disorder or impairment, or any medical condition or disability, because of their age, appearance or views, or because you consider the decision to be unwise or irrational. If, however, their decision is clearly contrary to previously expressed wishes, or based on a misperception of reality, this may be indicative of a lack of capacity and should be investigated further.

You must not assume that because a patient lacks capacity to make a decision on a particular occasion, they lack the capacity to make a decision at any other time. Some patients may also have capacity to make some decisions about their healthcare but not others; the difficulty, complexity or seriousness of the decision should be one of the factors taken into account when assessing the individual's capacity to make that decision. More information about assessing capacity can be found at: www.bma.org.uk/mentalcapacity.

It is important to note that despite the presumption of capacity from the age of 16, the situation regarding refusal of treatment is different for 16 and 17-year olds. For information about decision-making by and on behalf of, those aged 16-17, see our children and young people toolkit (available at www.bma.org.uk/ethics).

How should I assess whether someone has the capacity to consent?

Where there are grounds to question whether the patient has the capacity to make the decision in question, an assessment is required. This is a matter for clinical judgement, guided by professional practice and subject to legal requirements.

To demonstrate capacity to consent to treatment, individuals should be able to:

- understand in simple language what the medical treatment is, its purpose, nature and why it is being proposed;
- understand the benefits and risks of the treatment, and any alternative options;
- understand potential consequences of not having the treatment;

2

- retain the information for long enough to use it to make a decision; and
- communicate the decision (by any means).

In England and Wales (under the terms of the Mental Capacity Act), a person lacks capacity if their inability to do these things is caused by 'an impairment or disturbance in the functioning of the mind or brain'. For more information see the BMA's Mental Capacity Act toolkit, which is available at www.bma.org.uk/mentalcapacity.

What should I do if I am unsure about whether a patient has capacity to consent?

In some cases, it is clear that patients do not have capacity – for example, if they are unconscious. At other times the situation is less clear-cut. In these circumstances, you should take all reasonable steps to try and maximise a patient's ability to make, or contribute to, the decision that needs to be made. If you remain in doubt about someone's capacity to consent, you should seek further advice from others involved in the patient's care or a colleague with relevant specialist experience. Where there is uncertainty or disagreement about a patient's capacity that cannot be resolved, a court can be asked to decide.

What happens when a patient does not have capacity to consent?

In England and Wales, the Mental Capacity Act 2005 provides a comprehensive framework for decision-making on behalf of those aged over 16 who lack the capacity to consent (see our Mental Capacity Act toolkit). In Scotland this is covered by the Adults with Incapacity (Scotland) Act 2000 (see BMA guidance on the Act). In Northern Ireland, decision-making is currently covered by the common law but will be covered by the Mental Capacity Act (Northern Ireland) 2016 once it comes into force (up-to-date information and guidance will be provided on the ethics pages of the BMA's website). We also provide detailed guidance on decision-making on behalf of patients who lack capacity in our best interests decision-making toolkit (although this is based on the legislation in England and Wales, the principles and practical guidance it provides will also be relevant in other parts of the UK). All of this guidance can be found at www.bma.org.uk/mentalcapacity.

3

3. Sharing information with patients

Key points

- Patients require sufficient clear and accurate information, in a way they can understand, before providing consent.
- Information should be tailored according to the nature, complexity and level of risk of the proposed treatment, and the individual concerns, wishes and values of each patient.
- It is important to listen to the patient as well as providing information.
- Information should not be withheld at the request of others, such as family members.
- An individual's refusal to receive information should be respected although some basic information may need to be provided in order for the patient's consent to be valid.

What information should I share with patients to obtain their consent?

For patients to make decisions about their treatment and provide valid consent, doctors need to provide them with sufficient, clear and accurate information about any proposed course of action or treatment option. This includes information about:

- the purpose of the investigation or treatment;
- details and uncertainties of the diagnosis;
- options for treatment, including the option of no treatment;
- likely benefits and probabilities of success for each option;
- risks and potential side-effects, and adverse outcomes including the treatment not working;
- the name of the doctor with overall responsibility for their care;
- a reminder that a patient can change their mind about having the treatment at any time;
- reasons for any recommended treatment options; and
- if relevant, any foreseeable problems that could come to light while the patient is unconscious.

The discussions you have with patients should be tailored according to the nature and complexity of the proposed course of action, and the level of risk associated with it. They should also be tailored according to the individual concerns, wishes and values of each patient and their understanding of their condition and prognosis. For example, if the proposed treatment carries a potential risk of harm that you believe the patient would consider to be serious in their circumstances, you must tell the patient, even if you think it is very unlikely to occur. You should also tell patients about less serious side-effects or complications if they occur frequently, or if you think the patient may attach particular significance to them.

In March 2015, the UK Supreme Court (*Montgomery v Lanarkshire Health Board*) clarified that doctors must “*take reasonable care to ensure that the patient is aware of any material risks involved in any treatment, and of any reasonable alternative or variant treatments*”. A ‘material risk’ is one in which “*a reasonable person in the patient’s position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it*”.

3

Montgomery v Lanarkshire Health Board¹

Mrs Montgomery was an insulin-dependent diabetic. Diabetic women frequently have larger-than-normal babies, which leads to a heightened risk of a condition called shoulder dystocia where the baby's head may descend but the shoulders cannot pass through the pelvis without medical intervention.

Her consultant did not inform her of the 9-10% risk of shoulder dystocia, or of the possibility of delivery by caesarean section.

During delivery, following shoulder dystocia, the umbilical cord was occluded and her son was born with cerebral palsy and a paralysis of the arm, resulting from the vigorous manipulation required to deliver him.

Had he been delivered by caesarean section, he would have been a healthy baby.

The court held that the consultant should have informed Mrs Montgomery of the risks of shoulder dystocia and discussed the possibility of a caesarean section.

Although this reflects existing good practice, it is a significant judgment in that it means that doctors can no longer rely on the support of a responsible body of medical opinion ('the Bolam test') in deciding what information they should provide to patients. Instead, they must provide information about any risk to which the individual patient would attach significance.

When seeking consent, doctors therefore need to ask themselves the following questions.

- Is the patient aware of any risks relevant to his or her decision regarding the proposed treatment?
- Is the patient aware of any reasonable alternatives and their associated risks and benefits?
- Have I taken all reasonable measures to ensure that I have presented this information in a form the patient understands?
- Is the patient aware that they can refuse to have the treatment?

Should I withhold any information?

No. You should not withhold any information the patient needs to make a decision, including when a relative or carer asks you to. Failure to provide sufficient relevant information could be challenged in law.

There is some limited scope for doctors to withhold information where they have a reasonable belief that providing the information would cause the patient serious harm. The Supreme Court has made clear, however, that this exception should not be abused; it is designed to protect patients from serious harm, not to prevent them from making a choice the doctor considers to be contrary to their best interests.²

In some circumstances it may be appropriate to provide relevant information over a period of time, rather than providing it all at the same time. In such cases it should be clear from the medical record what information has already been shared, what information still needs to be

1 *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 (11 March 2015)
URL: <http://www.bailii.org/uk/cases/UKSC/2015/11.html>

2 *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 (11 March 2015), para 91
URL: <http://www.bailii.org/uk/cases/UKSC/2015/11.html>

3

shared, why some information was withheld and when, and how, the patient will be provided with it.

How should I share information with patients?

The GMC emphasises the importance of listening to patients and a shared decision-making process. In this process, the information your patients share with you, is as important as the information you give them.

Patients should be involved as much as possible in decisions about their own health and care, and should be given information about their treatment options in a way that they can understand. Doctors should take all reasonable steps to maximise patients' ability to understand, consider options and make a decision. This includes:

- taking time to understand the patient's values, wishes, and preferences and knowledge of their own condition;
- using clear and consistent language when discussing risks of harm and potential benefits;
- encouraging patients to ask questions;
- supporting patients with additional needs to have the time and any reasonable adjustments to make a decision;
- offering a record of your discussions if the patient may have difficulty retaining information;
- giving the patient time to reflect, before and after they make a decision;
- where appropriate, involving other members of the healthcare team in discussions;
- giving information that the patient may find distressing in a considerate way;
- sharing information at a time and place when you think the patient is most likely to be able to understand and retain it;
- supporting discussions with accurate written material, or visual or other aids;
- providing the opportunity for patients to discuss their options with others; and
- considering whether the patient might need more time with you or the healthcare team.

Before making a decision, you must check that your patients have understood the information they have been given and the language that you have used, or whether they need any more support to make a decision. You should ensure the patient is aware of any time limit on making their decision.

How should I answer any questions my patients may have?

Doctors should respond honestly and accurately to any questions patients may ask them. This includes discussing the nature and extent of any uncertainty regarding the clinical effect of a particular intervention.

If you are unable to answer a question, where possible you should find out the answer by consulting another professional or resource – or explain to the patient if there is an inherent uncertainty.

What if a patient does not want to know the information?

If a competent patient does not want to know the information, or make a decision, about their treatment, you should try to find out why and whether you can do anything to support them. Ultimately, however, patients retain the right not to be informed of the risks of a procedure – if a patient does not want to know, doctors are under no obligation to tell them.

3

Nevertheless, a minimum amount of basic information may need to be given in order for consent to be considered valid.³ Without basic information, patients may be unable to make a valid choice to delegate responsibility for treatment decisions to doctors. The amount of basic information needed depends upon the individual circumstances, the severity of the condition and the risks associated with the treatment.

You should explain why it is important for them to make an informed decision, and the potential consequences of them choosing not to receive information including, in some circumstances, being unable to proceed with the treatment.

Patients who refuse information should be advised that information can be provided at any time, should they change their mind, and a note should be made on the medical record that the patient has refused information.

What if I am not able to share information sufficiently, due to time and resource constraints?

If you are not able to share information sufficiently with your patients, because of pressures on your time or limited resources, you should consider the role of other members of the healthcare team in assisting you (see section 4). This might involve them gathering information and answering questions on your behalf. You should also consider other sources of information that are available such as patient information leaflets or support groups.

If there are factors outside your control which are compromising your patients' ability to make informed decisions, you should raise these concerns with your employer. Patients need to be given sufficient information for their consent to be valid.

3 Chatterton v Gerson [1981] QB 432.

4

4. Who is responsible for seeking consent?

Key points

- Clinical, legal and professional responsibility for ensuring that valid consent has been obtained rests with the person carrying out the procedure.
- Providing information and seeking consent may be delegated to a colleague, provided that person has the necessary knowledge, skills and experience.
- If you are asked to seek consent and do not feel competent to do so, you should inform the person who will be carrying out the procedure and ask for support; you should not seek consent if that support is not provided.
- If you are informed by the individual tasked with seeking consent that they do not feel competent to do so, you must ensure that support is provided or make alternative arrangements.

Whose responsibility is it to seek consent?

Clinical, legal and professional responsibility for ensuring that valid consent has been obtained before treatment is provided rests with the person carrying out the procedure. In some circumstances this may be delegated to a colleague, provided that person has the necessary knowledge, skills and experience.

The General Medical Council is clear that the doctor undertaking an investigation or providing treatment, is responsible for ensuring they have valid consent or other authority before commencing the procedure or treatment.

Part of the consent process may be delegated to other members of the team, but the doctor carrying out the treatment must be sure the person they are delegating to:

- is suitably trained and qualified;
- has sufficient knowledge and skills; and
- feels competent to carry out the tasks requested.

Your decision about whether delegating is appropriate should depend on the complexity of the intervention, the level of uncertainty surrounding the outcome, your relationship to the patient and any concerns the patient may have. If you are the doctor being delegated to, you must make sure you have sufficient knowledge and expertise to obtain consent from the patient.

What if I am asked to seek consent but do not feel competent to do so?

It is your responsibility to ensure you have sufficient knowledge and expertise to provide information, answer questions and seek consent for common procedures in the specialty within which you are working. If, in a particular case however, you do not feel that you have sufficient information or expertise to comply with the request, you should inform the person who will be carrying out the procedure. You should not comply with a request to seek consent if, having raised these concerns, appropriate support is not provided.

4

What if the person I ask to seek consent raises concerns about doing so?

If you are informed by the individual tasked with seeking consent that he or she does not have the necessary knowledge or skills to comply with the request, you must ensure that support is provided, or make alternative arrangements, to ensure that valid consent is obtained.

If you delegate responsibility for seeking consent to someone who does not have the necessary knowledge and skills, you must accept overall responsibility for any failings in the consent process.

5

5. Refusal of consent

Key points

- Competent adult patients can refuse to consent to any treatment and such refusals must be respected. The only exception is where compulsory treatment for the patient's psychiatric disorder is authorised by mental health legislation.
- Competent adult patients can refuse food and fluids – whether provided orally or by tube (clinically-assisted).
- An advance decision refusing food and fluids orally will not be legally binding. Oral feeding should continue to be offered to, but not forced upon, all patients who are capable of swallowing safely
- Patients are not required to justify their decisions but doctors must ensure they have based their decision on accurate information and correct any misunderstandings.

Can patients refuse to consent to treatment?

Yes. Competent adult patients (those over the age of 18) can refuse to consent to any treatment except where compulsory treatment for the patient's psychiatric disorder is authorised by mental health legislation (see section 8). The situation is different for patients under the age of 18; for more information on this see the BMA's children and young people toolkit which is available at: www.bma.org.uk/ethics.

Doctors must respect a patient's decision to refuse treatment, even if they do not agree with it or when it could lead to permanent injury or death. For example, a Jehovah's Witness can refuse a blood transfusion even where this is essential for survival. Providing treatment without valid consent, and in the face of a competent refusal, would leave the doctor open to legal and professional sanctions.

A refusal of treatment should not be interpreted as a refusal of all treatment or care. It is essential that steps are taken to keep the patient comfortable and that any symptoms or distress are appropriately managed.

Can patients refuse food and fluids?

Yes. Competent adult patients can refuse food and fluids – whether provided orally or by tube (clinically-assisted) – and such refusals must be respected. It should be made clear to such patients, however, that they can change their minds and accept food and/or fluids at any time.

Whilst a valid and applicable advance decision to refuse clinically-assisted nutrition and hydration will be legally binding once a patient loses capacity (see section 6), an advance refusal of oral feeding (which forms part of 'basic care') will not be. Oral feeding should continue to be offered to, but not forced upon, all patients who are capable of swallowing safely.

Do patients need to justify their decision to refuse consent?

No. Patients are not required to justify their decision to refuse consent, but health professionals should seek to ensure that patients base their decisions on accurate information and that they have corrected any misunderstandings. Patients also need to know if refusing treatment now will limit their future options.

Doctors must not put pressure on patients to decide in a particular way, but should allow them time to consider a decision with potentially serious consequences.

6

6. Advance care planning

Key points

- Patients who have capacity should be encouraged to think about what they would want to happen in the future if they are unable to express their views about treatment.
- Advance requests for treatment are not legally binding but will be taken into account, once capacity is lost, as part of the best interests assessment.
- Valid and applicable advance decisions refusing treatment are legally binding in England and Wales and are likely to be binding in Scotland and Northern Ireland.
- Patients who wish to plan for a future loss of capacity can formally appoint someone as an attorney with the power to make health and care decisions on their behalf.

Can a patient plan for future treatment once capacity is lost?

Yes. It is a good idea to encourage patients to think about what they would want to happen in the future if they are unable to express views about treatment for themselves. This is particularly important where loss of capacity is a foreseeable possibility, or where the patient may find it difficult to make decisions in the future. It is also useful for patients to consider these issues in circumstances where decisions may need to be made quickly at a later stage, or when they have a condition that will affect the length or quality of their life.

Doctors should take all reasonable steps to plan for foreseeable changes in a patient's capacity to make a decision, and help patients to make decisions at a time when they are able to do so. They should encourage patients to think about what they might want in the event of different outcomes, and to discuss this with the healthcare team and those close to them. These discussions should cover:

- the patient's wishes, concerns or personal beliefs in relation to their future care;
- any treatments they would want provided, or to refuse, and under what circumstances; and
- any interventions that might become necessary during an emergency.

Doctors must record the discussions in the patient's medical record and document any views or decisions the patient expresses.

Can patients request treatment in advance?

Advance requests for treatment are not legally binding, but they should be taken into account in assessing whether the treatment would be in the patient's best interests. It is, however, part of a doctor's duty of care to take reasonable steps to keep a patient alive where that is the patient's known wish.⁴

Can patients refuse treatment in advance?

Yes. If a patient has clear views about treatments they would want to refuse, and the circumstances in which they would want to refuse them, they should be informed of the possibility of making a formal advance decision to refuse treatment (ADRT), sometimes referred to as a 'living will'. Where a patient lacks capacity to make decisions and has an ADRT that is valid and applicable to the circumstances that have arisen, it will be legally binding on the doctors treating the patient.

⁴ *R (on the application of Burke) v General Medical Council* [2005] 2 FLR 1223.

6

When are ADRTs legally binding?

In England and Wales, advance decisions to refuse treatment are covered by the Mental Capacity Act (see our Mental Capacity Act toolkit at www.bma.org.uk/mentalcapacity). An ADRT will be legally binding if:

- it was made by someone aged 18 or older who had capacity to make the decision at the time it was written;
- it clearly applies to the treatment to be refused in the circumstances that have arisen;
- it has not been withdrawn;
- the individual has not, after the ADRT was made, appointed a health and welfare attorney (see below) to make the specific decision; and
- the person making the decision has not done anything clearly inconsistent with the decision remaining a fixed decision.
- If the advance decision is to refuse life-sustaining treatment, it must meet the **additional** following criteria:
 - it must be made in writing, signed and witnessed; and
 - must include a statement that it is to apply even where life is at risk.

In Scotland, advance refusals of treatment are referred to as advance directives. They are not covered by the Adults with Incapacity (Scotland) Act 2001 but are likely to be binding under the common law. Similarly, in Northern Ireland the common law rules relating to advance decisions to refuse treatment will apply (more detailed information may be provided in the code of practice once the Mental Capacity (Northern Ireland) Act 2016 is implemented). Patients in Scotland and Northern Ireland wishing to ensure that their advance refusal is legally binding should be advised to follow the criteria set out above.

How should ADRTs be stored and recorded?

Patients who have made an advance decision/directive should be encouraged to provide a copy to be stored on their medical records. They should also ensure that those family members or friends who are likely to be consulted in an emergency are aware of its existence and can easily locate it. It is the patient's responsibility to ensure that the document is available when needed and doctors do not need to spend time searching for an ADRT if there is no indication that one exists. Nevertheless, doctors who are informed of the existence of an ADRT must take steps to find it and doctors who receive enquiries about the existence of an advance decision from another health professional, should provide them with a copy of the document without delay.⁵

Can patients appoint someone to make decisions on their behalf?

Another option for patients who wish to plan for a future loss of capacity is to formally appoint someone as an attorney with the power to make health and care decisions on their behalf (in England and Wales these are called lasting powers of attorney or LPAs). In England, Wales and Scotland, where the appropriate process has been followed, the attorney will be the lawful decision-maker. In Northern Ireland, the same will be true once the new legislation comes into force. If a health and welfare attorney is appointed after an advance decision has been made, this will affect the validity of the ADRT (see above). For more information about the role of health and welfare attorneys see our guidance at www.bma.org.uk/mentalcapacity.

⁵ *NHS Cumbria CCG v Rushton* [2018] EWCOP 41

7

7. Consent for emergency treatment

Key points

- In an emergency situation, if the patient has capacity, consent must be obtained before treatment is provided.
- Where it is not possible to obtain consent, doctors should provide treatment that is in the patient's best interests and is immediately necessary to save life or avoid significant deterioration to the patient's health.
- If the patient has appointed a welfare attorney, or there is a court-appointed deputy or guardian, this person must be consulted about treatment decisions, where time permits.

Does consent need to be sought for emergency treatment?

Yes, if the patient has the capacity to give consent.

If the patient is unable to give consent, can treatment be provided in an emergency situation?

In an emergency, where it is not possible to obtain consent, doctors should provide treatment that is in the patient's best interests and is immediately necessary to save life or avoid significant deterioration to the patient's health. More information can be found in our best interests toolkit, which is available at: www.bma.org.uk/mentalcapacity.

If the patient is an adult, and there is clear evidence of a valid and applicable advance refusal of a particular treatment, that treatment should not be given (for example, a refusal of a blood transfusion by a Jehovah's Witness). If the patient has appointed a welfare attorney, or there is a court-appointed deputy or guardian, this person must be consulted about treatment decisions, where practical (see section 6).

8

8. Compulsory treatment under mental health legislation

Key points

- Treatment for a mental disorder can be provided without consent if it is authorised under mental health legislation.
- Mental health legislation cannot impose on patients treatment for physical ailments not arising from a mental disorder.
- Advance decisions refusing treatment for a mental disorder can be overruled if the individual is being treated compulsorily under mental health legislation.

Can treatment be provided to a patient without seeking consent if they are detained under mental health legislation?

Mental health legislation permits doctors to treat a patient compulsorily for a mental illness, without their consent. This includes treatment for physical conditions arising directly from a psychiatric condition such as forced re-nutrition in patients with anorexia nervosa or treating wounds self-inflicted as the result of a mental disorder. However, it is still good practice to explain to the patient the treatment that will be provided, and where possible, to seek their agreement.

Treatment can only be authorised under mental health legislation if it is treatment for the mental illness and the legislation specifically excludes imposing treatments for other physical conditions. Consent is still, therefore, required for other forms of treatment, even if the patient is detained under mental health legislation.

Legislation has been passed in Northern Ireland, but is not yet in force, that will remove the ability to provide compulsory treatment for mental disorders for patients who have capacity. Information and guidance on the legislation will be provided on the BMA's website once it comes into force.

Are advance decisions overruled when a patient is detained under mental health legislation?

Advance decisions can be overruled if the individual is being treated compulsorily under mental health legislation, with regards to treatment for the mental illness. A valid and applicable refusal of treatment for conditions that are *not* covered by the mental health legislation will still be binding (see section 6).

9

9. Consent for research

Key points

- Consent is required for competent adults to participate in research.
- Consent is required in England, Wales and Northern Ireland for the use of tissue from living individuals for research unless the tissue samples are anonymised and the research has been approved by a research ethics committee.
- In Scotland, there is no legal obligation to seek consent for the use of tissue from living individuals for research although research ethics committees may require consent where the material is identifiable.

Is separate consent required for research procedures?

Yes. Doctors must ensure that patients asked to consider taking part in research are given clear information, presented in a way they can understand. Patients should be made aware that they are being asked to take part in a research project and that the results are not predictable. Adequate time must be given for reflection prior to the patient giving consent. Where patients do not wish to receive full information about the research, this may affect the doctor's decision to involve them.

What information should be provided to obtain valid consent to participate in research?

Information should preferably be provided in writing and should be approved in advance by a research ethics committee. It should include:

- the purpose of the research and what it involves;
- information about research-related procedures – particularly invasive procedures;
- the probability of random allocation to treatment, if appropriate;
- the fact that patients can withdraw from the research at any time, without penalty or any adverse effect on the care they receive (but that once data or samples have been anonymised, it will no longer be possible to withdraw consent for their use);
- any financial arrangements in place, such as for covering patients' expenses and compensation in the event of trial-related injury;
- information about confidentiality and the possibility of access to confidential notes by third parties (such as regulatory authorities, auditors or ethics committees); and
- what, if any, information they can expect to receive about the research findings and conclusions.

Is consent required for the use of human tissue for research?

Under the Human Tissue Act 2004 (England, Wales and Northern Ireland) if the samples are anonymised and the research has been approved by a research ethics committee, consent is not required. In other circumstances, consent must be obtained and documented before the storage and use of a living person's organs, tissues or cells, for the purpose of research.

The Human Tissue (Scotland) Act 2006 does not cover the use of tissue from living individuals. There is, therefore, no legal obligation to seek consent for the use of tissue from living individuals in Scotland, although research ethics committees may require consent to be obtained where the tissue is used in identifiable form.

10

10. Consent for teaching purposes

Key points

- Consent should be sought for medical students or other observers to be present during a consultation or treatment.
- Specific consent must be obtained to carry out any practical procedures on patients whilst they are anaesthetised, for training purposes.
- Doctors must obtain consent from the patient prior to a recording being made and for its subsequent use for teaching purposes.
- Consent is not required for the storage and use of material from living individuals for teaching purposes provided it is anonymised. The use of identifiable samples for teaching requires consent.

Is it necessary to seek a patient's consent for medical students or other observers to be present during a consultation or treatment?

Yes. The doctor carrying out the consultation should explain to the patient that an observer would like to sit in on the consultation, who that person is and why they would like to observe. Patients should feel able to say no, knowing that it will not impact on their treatment in any way.

Wherever possible, patients should be given the option of considering the request before the arrival of the observers.

Is specific consent required to teach practical procedures on a patient who has been anaesthetised?

Yes. Before any anaesthetic is given, specific consent must be obtained from the patient, to carry out any practical procedures on them for teaching purposes.

Is it necessary to seek consent from patients for the use of visual and audio recordings of procedures, for teaching purposes?

Yes. Doctors must obtain consent from the patient prior to a recording being made and for its subsequent use for teaching purposes.

Patients may withdraw their consent to the use of visual and audio recording for teaching purposes at any time. If they do so, the recordings must be erased.

What type of consent is required for the use of human tissue for educational purposes?

Consent is not required for the storage and use of material from living individuals for teaching purposes, provided it is anonymised. The use of identifiable samples for teaching requires consent.



11. Further reading

British Medical Association (2016) *Mental Capacity Act toolkit*.

British Medical Association (2019) *Best interests decision-making for adults who lack capacity. A toolkit for doctors working in England and Wales*

British Medical Association (2011) *Taking and using visual and audio recordings of patients* (updated February 2019)

British Medical Association (2009) *Medical treatment for adults with incapacity: Guidance on ethical and medico-legal issues in Scotland*.

British Medical Association and the Law Society (2015) *Assessment of Mental Capacity: A Practical Guide for Doctors and Lawyers, fourth edition*.

General Medical Council (2008) *Consent – Patients and doctors making decisions together*.

General Medical Council (2010) *Good practice in research; and Consent to research (both updated in March 2013)*

General Medical Council (2007) *0-18 Years: Guidance for all Doctors (updated May 2018)*

Department of Health (2009) *Reference guide to consent for examination or treatment, second edition*.



BMA

British Medical Association, BMA House,
Tavistock Square, London WC1H 9JP
bma.org.uk

© British Medical Association, 2019

BMA 20190526