# Ethics Toolkit

## Treating 16 and 17-year-olds in England, Wales, and Northern Ireland

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BMA Medical ethics and human rights

bma.org.uk

# Contents

# About this toolkit

When they reach the age of 16, all young people in the UK are assumed in law to have the capacity to make their own decisions about medical treatment and in Scotland, young people are classed as adults from that age. It is not until they reach the age of 18, however, that they are treated in the same way as adults in every area of medical law, and this can make decision making for this group complex. As a result, in the past some of the answers doctors seek were found in our guidance on children and young people, some in our Consent and refusal by adults with decision-making capacity toolkit, and some in our guidance on adults who lack capacity to consent.

To make our guidance as helpful and as accessible as possible we have produced this separate guidance on treating 16 and 17-year-olds in England, Wales, and Northern Ireland, bringing together in one place the key information doctors need to know when treating that group of patients. There is a separate toolkit on the treatment of 16 and 17-year-olds in Scotland.

For healthcare professionals who need guidance on the treatment of children and young people under the age of 16, the BMA has published a children and young people under 16 toolkit.

The toolkit is available on the BMA's website. Individual healthcare professionals, trusts, health boards, and medical schools may download it and make copies.

The BMA would welcome feedback on the usefulness of the toolkit. If you have any comments, please address them to:

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# 1 Introduction

When they reach the age of 16, all young people in the UK are assumed in law to have the capacity to make their own decisions about medical treatment and in Scotland, young people are classed as adults from that age. It is not until they reach the age of 18, however, that they are treated in the same way as adults in every area of medical law, and this can make decision making for this group complex. As a result, in the past some of the answers doctors seek were found in our guidance on children and young people, some in our Consent and refusal by adults with decision-making capacity toolkit, and some in our guidance on adults who lack capacity to consent.

To make our guidance as helpful and as accessible as possible we have produced this separate guidance on treating 16 and 17-year-olds in England, Wales, and Northern Ireland, bringing together in one place the key information doctors need to know when treating that group of patients. There is a separate toolkit on the treatment of 16 and 17-year-olds in Scotland (see key resources)

For healthcare professionals who need guidance on the treatment of children and young people under the age of 16, the BMA has published a children and young people under 16 toolkit (see key resources).

## Key resources

BMA – Consent and refusal by adults with decision-making capacity
BMA – Best interests decision-making for adults who lack capacity toolkit
BMA – Treatment of 16 and 17-year-olds in Scotland toolkit
BMA – Children and Young People under 16 toolkit
GMC – 0-18 years

# 2 Consent and refusal of treatment

## Consent to treatment

### Are 16 and 17-year-olds able to consent to treatment?

When a young person reaches the age of 16, they are assumed to have legal capacity to give consent, in accordance with section 8 Family Law Reform Act 1969. Where there is doubt about the young person's capacity, this should be assessed in line with the guidance set out in section 5.

### Who can consent to or authorise treatment for a 16 or 17-year-old?

The following are legally entitled to give consent to medical treatment for a 16 or 17-year-old in England, Wales, and Northern Ireland:

- the 16 or 17-year-old unless they lack capacity (see section 4 on capacity and incapacity and section 5 on assessing capacity);
- a parent or other person or agency with parental responsibility where they are asked to do so by the young person, or where the young person lacks capacity, and the decision is in their best interests (see sections 6 and 7 on best interests and parental responsibility). There are some exceptions to this, such as the use of restrictive practices that amount to a deprivation of liberty (DoL) (see section 10); and
- a court.

In addition, where a 16 or 17-year-old lacks capacity to make a decision, in England and Wales, the Mental Capacity Act (MCA) 2005, and in Northern Ireland, the common law, allows the healthcare professional in charge of their care to provide treatment without consent, where it is in their best interests. This means that where a 16 or 17-year-old lacks capacity, there are two separate routes through which treatment that is in the young person's best interests can be authorised: consent from those with parental responsibility and by healthcare professionals in accordance with the MCA in England and Wales, or the common law in Northen Ireland.

In a situation where there is a choice to be made between the two frameworks, in deciding whether the particular decision can be taken on the basis of parental consent, healthcare professionals need to consider a range of factors to establish whether the decision falls within the scope of parental responsibility:

- is this a decision that a parent should reasonably be expected to make? Significant factors determining this are likely to include:
  - the type and invasiveness of the proposed intervention;
  - the extent to which the decision accords with the wishes of the young person; or
  - whether the young person is resisting the decision.
- are there any factors which might undermine the validity of parental consent?
  - where the parent may lack capacity because of their own impairments;
  - where parents disagree about what is best for their child and what action should be taken; or
  - where the parent is not able to focus on what course of action is in their child's best interests, as a result of their own hostilities.

Deciding on whether it is appropriate to rely on parental consent, or to provide treatment without consent where it is in the young person's best interests, can cause confusion but, in practical terms, healthcare professionals and those with parental responsibility should try to reach agreement about what would be in the young person's best interests. Where agreement cannot be reached, or if there is doubt about whether or not parental consent can be relied on to authorise the particular intervention, healthcare professionals should follow the process set out in section 8 for

2

resolving disputes and seek legal advice.

### Are there any procedures a 16 or 17- year-old cannot consent to?

There are some rare procedures, for example live organ donation, where a 16 or 17-year-old cannot provide consent, and for which a court order is required.

There are also some provisions relating to healthcare for adults that do not apply to 16 and 17-year-olds, namely they cannot make a legally binding Lasting Power of Attorney (LPA) or an advance decision to refuse medical treatment (ADRT). In the event that a young person under 16 were to document their views and wishes about treatment and were subsequently to lose their ability to take part in decisions, their documented wishes (although not binding) would be relevant to the determination of the young person's best interests and should be taken into account.

### Are there any procedures for 16 and 17-year-olds who lack capacity that need additional safeguards?

Case law and Court of Protection guidance in England and Wales have made clear that in certain categories of cases legal advice should be sought to determine whether an application to court is required, and the BMA recommends that doctors in Northern Ireland should also seek legal advice in cases where:

- at the end of the decision-making process:
  - the decision is finely balanced;
  - there is a difference of medical opinion;
  - there is a doubt or dispute that cannot be resolved locally about whether a particular treatment will be in a person's best interests; or
  - there is a conflict of interest on the part of those involved in the decision-making process that cannot be appropriately managed.
- a medical procedure or treatment is for the primary purpose of sterilisation;
- the procedure is for the purpose of donation of an organ, bone marrow, stem cells, tissue, or bodily fluid to another person;
- the action proposed involves a procedure for the covert insertion of a contraceptive device or other means of contraception;
- it is proposed that an experimental or innovative treatment be carried out; or
- the case involves a significant ethical question in an untested or controversial area of medicine.

An application to court may also be required where the proposed procedure or treatment will require a degree of force to restrain the person concerned and the use of restraint constitutes a deprivation of liberty (see section 10).

## Refusal of treatment

### Is the refusal of a 16 or 17-year-old binding in England, Wales, and Northern Ireland?

No, not always. In England, Wales, and Northern Ireland, a refusal by 16 or 17-year-old who has capacity can be overruled by a court. Healthcare professionals faced with an informed refusal of a treatment they believe to be in the patient's best interests, for example a refusal of lifesaving treatment or treatment that would prevent permanent injury, should take legal advice.

Whilst in the past the courts in England and Wales have found that a person with parental responsibility can override a refusal by a young person with capacity, recent case law in England has given greater weight to a young person's views and suggests a growing trend towards increasing respect for autonomy. If a 16 or 17-year-old has capacity and refuses treatment,

2

healthcare professionals **should not** therefore rely upon consent from a person with parental responsibility to override their decision but should seek legal advice with a view to making an application to court. Although decisions in the English High Court are not binding in Northern Ireland, it is also likely to be the case that a person with parental responsibility cannot override a refusal from a 16 or 17-year-old, and it is therefore advisable to seek legal advice.

Before making an application to court however, doctors must consider whether the harms associated with imposing treatment on a 16 or 17-year-old who refuses, outweigh the potential benefits, how critical the treatment is, whether alternative less invasive treatments are available, and whether it is possible to allow time for further discussion with the young person. As much time as is practicable should be taken for discussion, and treatment delayed if that is possible without jeopardising its likely success.

If a young person with capacity does not consent or refuses to consent to treatment but is happy to defer the decision to a parent who has parental responsibility, that person retains the responsibility and the power to provide consent.

## Treatment in emergencies

### In an emergency, where consent cannot be obtained on what basis can a 16 or 17-year-old be treated?

As with adults, in an emergency, where consent cannot be obtained, for example when a 16 or 17-year-old is unconscious, it is legally and ethically appropriate for healthcare professionals to proceed with the treatment necessary to preserve the life, health, or wellbeing of the young person. An emergency is best described as a situation where the requirement for treatment is so pressing that there is no time to refer the matter to court. If such an emergency involves administering a treatment to which the young person is known or believed to object, for example, the administration of blood to a Jehovah's Witness, viable alternatives should be explored if time allows. In extreme situations, however, healthcare professionals are advised to take all essential steps to stabilise the young person. Legal advice may be needed once emergency action has been taken.

### Key resources

BMA – Mental Capacity Act England and Wales toolkit
BMA – Mental Capacity in Northern Ireland toolkit
GMC – 0-18 years

# 3 Seeking consent from 16 and 17-year-olds

## When is it necessary to seek consent?

Doctors must obtain consent from 16 and 17-year-olds who have the capacity to give it any time they wish to initiate an examination, treatment, or any other intervention. Consent is also required for the participation of 16 and 17-year-olds in research (see section 15).

As with adults, the only exceptions to this are in emergencies where it is not possible to obtain consent (see section 2), or when the law prescribes otherwise, such as when compulsory treatment for a 16 or 17-year-old's psychiatric disorder is authorised by mental health legislation (see section 14). 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 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, 16 and 17-year-olds 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.

## 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.

The General Medical Council (GMC), at paragraph 5 of its guidance *Decision making and consent*, advises that doctors can apply their own professional judgement about the most appropriate way to seek consent which will be dependent on the specific circumstances of each decision, including:

'a. the nature and severity of the patient's condition and how quickly the decision must be made
b. the complexity of the decision, the number of available options and the level of risk or degree of uncertainty associated with any of them
c. the impact of the potential outcome on the patient's individual circumstances
d. what you already know about the patient, and what they already know about their condition and the potential options for treating or managing it
e. the nature of the consultation.'

The GMC also advises, at paragraph 7, that whilst it would be reasonable for a doctor to rely on a patient's non-verbal consent for some routine, quick, minimally, or non-invasive interventions, doctors should still:

'a. explain what is going to be done and why
b. make clear the patient can say no, and stop immediately if they do
c. be alert for any sign that the patient may be confused or unhappy about what you are doing.'

3

## Does consent always need to be in writing?

No. Written consent is only legally required for a small number of treatments (such as some forms of fertility treatment) although 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 16 or 17-year-old 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. Like adults, 16 or 17-year-olds 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;
- there is new information available;
- there have been any significant changes to the patient's condition; or
- 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.

## 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.

## Key resources

BMA – Consent and refusal by adults with decision-making capacity
Department of Health and Social Care (DHSC) – Reference guide to consent for examination or treatment
GMC – Decision making and consent

# 4 Capacity and incapacity

## What is capacity?

Decision-making capacity refers to the everyday ability we possess to make decisions or to take actions that influence our lives, from simple decisions about what to have for breakfast, to complex decisions about serious medical treatment. In a legal context it refers to a person's ability to do something, including making a decision, which may have legal consequences for themselves or for other people.

Young people aged 16 and over are presumed in law to have capacity to give their consent to medical treatment in England, Wales, and Northern Ireland. This means that it is never for the 16 or 17-year-old to prove their own capacity. Where a person intends to take steps on the basis that the young person lacks capacity to make the relevant decision, that person must be able to explain why they consider that they are allowed to do so, including why the young person can be said to lack capacity.

## When does a 16 or 17-year-old lack capacity in England and Wales?

In England and Wales, from the age of 16 decisions about treatment for patients who lack capacity are covered by the Mental Capacity Act 2005. For the purposes of the MCA, a 16 or 17-year-old lacks capacity if, at the time the decision needs to be made, they are unable to make or communicate the decision because of an 'impairment of, or a disturbance in the functioning of, the mind or brain'. This could be the result of a variety of factors, including mental illness, learning disability, dementia, brain damage, or intoxication. The inability to make the decision, however, must be a result of that impairment or disturbance (this is sometimes referred to as the 'causative nexus').

The Supreme Court has confirmed that the correct way to apply the test is as follows:

1. Is the person able to make the decision in question at the time it needs to be made? If they cannot:
2. Is there an impairment or disturbance in the functioning of the person's mind or brain? If so:
3. Is the person's inability to make the decision because of the identified impairment or disturbance?

The assessment of capacity is 'task specific'. It focusses on the specific decision that needs to be made at the specific time the decision is required. It does not matter if the incapacity is temporary, or the person retains the capacity to make other decisions, or if the person's capacity fluctuates.

## When does a 16 or 17-year-old lack capacity in Northern Ireland?

Most healthcare decisions for 16 and 17-year-olds in Northern Ireland are covered by the common law. Under the common law in Northern Ireland (set out in the Appeal Court case of Re MB), a person lacks capacity if:

'some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent or to refuse treatment'.

An impairment or disturbance of mental functioning could be the result of a variety of factors, including mental illness, learning disability, dementia, brain damage, or intoxication.

# 4

A 16 or 17-year-old lacks the capacity to make a decision if, at the time the decision needs to be made, they are unable to:

- understand the information relevant to the decision;
- retain the information;
- use or weigh the information as part of the process of making a decision; or
- communicate the decision.

The assessment of capacity is 'task specific'. It focusses on the specific decision that needs to be made at the specific time the decision is required. It does not matter if the incapacity is temporary, or the person retains the capacity to make other decisions, or if the person's capacity fluctuates.

Decisions relating to deprivation of liberty and participation in research are covered by the Mental Capacity Act (Northern Ireland) 2016 (MCA NI) which provides a statutory definition of what it means to lack capacity to consent for these purposes. Some of this information can be found in section 10 on restraint and other restrictive practices and section 15 on research. More detailed information is in the BMA's Mental capacity in Northern Ireland toolkit (see key resources).

## Key Resources

BMA – Mental Capacity Act England and Wales toolkit
BMA – Mental capacity in Northern Ireland toolkit

5

# Assessing capacity

## What are the basic principles of assessing capacity?

The Mental Capacity Act 2005 (MCA), in England and Wales, and the common law in Northern Ireland, set out several principles that govern decision making for 16 and 17-year-olds. Actions or decisions that clearly conflict with these principles are unlikely to be lawful, although there may be occasions where they are in tension, and some balancing will be required. A list of the principles, with brief descriptions, is given below.

## A presumption of capacity

All young people aged 16 and over are presumed in law to have capacity to give their consent to medical treatment in England, Wales, and Northern Ireland. This means that it is never for the 16 or 17-year-old to prove their own capacity. Where a person intends to take steps on the basis that the young person lacks capacity to make the relevant decision, that person must be able to explain why they consider that they are allowed to do so, including why the young person can be said to lack capacity.

## Maximising decision-making capacity

Closely linked to the presumption of capacity, this principle requires that everything practicable must be done to support an individual to make their own decisions before it is decided that they lack capacity to make the decision(s) in question. For example, advocates and communication support might be necessary, and consideration given to whether an individual's decision-making abilities are affected by the time of day or medication regimes. The aim is to ensure that individuals who can make decisions for themselves but may, nevertheless, need some support, are not inappropriately assessed as lacking capacity.

## The freedom to make unwise decisions

The fact that an individual makes a rash, unwise or irrational decision, or acts out of character, is not in and of itself proof of incapacity. All 16 or 17–year olds retain the right to make decisions which seem unwise or irrational to others. Although such actions may raise questions about capacity – where for example they follow a period of illness or an accident – they are not determinative of capacity. What matters is the ability to make the decision, not the content of the decision per se. This means that while an unwise decision might be a reason to consider whether the young person has capacity, it cannot be the basis on which they are found to lack capacity.

## Best interests

Where individuals lack capacity, any decision or action taken on their behalf must be in their best interests. Practically speaking, what constitutes an individual's best interests will depend upon the circumstances. Further information about best interests can be found in section 6. The BMA also has a separate toolkit on best interests decision making for adults who lack capacity. Although this is based on the legislation in England and Wales, much of the practical information and guidance will also be helpful to doctors practising in Northern Ireland (see key resources).

## The less-restrictive alternative

Whenever a person is making a decision on behalf of a 16 or 17-year-old who lacks capacity, they must consider if it is possible to make the decision in a way that is less restrictive of that individual's fundamental rights or freedoms. There are often several ways to achieve a desired outcome, and where possible the choice must be the one that interferes least with the individual's freedoms while still achieving the necessary goal. The option chosen must, however, be in the person's best interests, which may not in fact be the less restrictive.

5

## Who should assess capacity?

The law does not specify who should assess capacity where a patient's ability to make a decision has been called into question. In its guidance on decision making and consent at paragraph 82 the GMC states:

'Assessing capacity is a core clinical skill and doesn't necessarily require specialist input (for example, by a psychiatrist). You should be able to draw reasonable conclusions about your patient's capacity during your dialogue with them. You should be alert to signs that patients may lack capacity and must give them all reasonable help and support to make a decision.'

Healthcare professionals who assess capacity need to be skilled and experienced in discussions with young people and eliciting their views. The treating doctor may be the most appropriate person, but other members of the healthcare team, or someone close to the young person may also have valuable contributions to make. The healthcare professional providing the treatment must be satisfied that the young person has capacity before providing the treatment if they are relying on their consent. Although assessing capacity is a core clinical skill, in complex cases where there is doubt about whether the 16 or 17-year-old has the requisite capacity, you should seek specialist input from colleagues such as psychiatrists or psychologists. You should also seek specialist input if the young person, or someone close to them, disagrees with your assessment.

## How do you assess capacity?

When assessing a 16 or 17-year-old's capacity to make a specific treatment decision, healthcare professionals should ensure, as far as possible, that any factors likely to affect their ability to decide for themselves are addressed beforehand. These may include medication, medical condition, pain, time of day, fatigue, or mood. Any information must be given as clearly and plainly as possible, with communication aids used where appropriate. Those assessing a 16 or 17-year-old's capacity are also under an obligation to enhance their capacity as far as reasonably possible. This will involve seeking to ensure that the young person is engaged in decision making when they are best able to participate and are encouraged to participate in decision making to the greatest extent they are able.

## England and Wales

In England and Wales, the MCA makes use of a 'functional' test of capacity, adapted from the common law, which focusses on the decision-making process itself. There are three elements to the assessment of capacity:

1. an inability to make a decision (the functional test);
2. an impairment of, or a disturbance in the functioning of the mind or brain (the impairment/disturbance test); and
3. a causal link between the two (in other words the inability to make a decision must be caused by the impairment).

Under the functional test, a 16 or 17-year-old is regarded as being unable to make a decision if, at the time the decision needs to be made, they are unable, even with all practicable support to:

- understand the information relevant to the decision;
- retain the information relevant to the decision;
- use or weigh the information; or
- communicate the decision (by any means).

Where a 16 or 17-year-old fails one or more parts of this test, they do not have the relevant capacity. Difficult judgements will still need to be made, particularly where capacity fluctuates; where some capacity is demonstrable,

5

but its extent is uncertain; or where the impairment – which does not require a formal diagnosis – may interact with coercion or duress from those close to the young person.

If the impairment which is causing the inability to make a decision is temporary, and the decision can reasonably be put off until such time as the young person is likely to regain capacity, then it should be deferred.

A 16 or 17-year-old should not be assessed as lacking capacity until all reasonable steps have been taken to assist them to make the decision and an assessment that a young person lacks the capacity to make a decision must not be discriminatory. It must not be based simply on:
- age;
- appearance;
- assumptions about their condition; or
- any aspect of their behaviour.

When assessing capacity, consideration should be given, where appropriate, to the views of those close to the 16 or 17-year-old. Parents may be able to provide valuable background information, although their views about what they might want for the young person must not be allowed to influence the assessment of capacity.

The MCA requires that any decision that a young person lacks capacity must be based on a 'reasonable belief' backed by objective reasons. Where there are disputes about whether a young person lacks capacity that cannot be resolved using more informal methods, the Court of Protection can be asked for a ruling. More detailed advice on assessing capacity is available from other sources (see key resources).

## Northern Ireland

In Northern Ireland, in relation to medical treatment, doctors should follow the common law which states that a 16 or 17-year-old lacks capacity 'if an impairment or disturbance of mental functioning renders them unable to make a decision'. That inability to make a decision occurs when they are unable to:
- understand the information relevant to the decision;
- retain the information;
- use or weigh that information as part of the process of making the decision; or
- communicate the decision.

Where a 16 or 17-year-old fails one or more parts of this test, they do not have the relevant capacity. Difficult judgements will still need to be made, particularly where capacity fluctuates; where some capacity is demonstrable, but its extent is uncertain; or where the impairment – which does not require a formal diagnosis – may interact with coercion or duress from those close to the young person. If the incapacity is temporary and the decision can reasonably be put off until such time as the young person is likely to regain capacity, then it should be deferred.

The parents of a 16 or 17-year-old may be able to provide valuable background information about the young person to assist with the assessment of capacity, although their views about what they might want for the individual must not be allowed to influence the assessment of capacity.

5

## What do you do if a 16 or 17-year-old refuses to be assessed?

Occasionally a young person whose capacity is in doubt may refuse to be assessed. In most cases, a sensitive explanation of the potential consequences of such a refusal, such as the possibility that any decision they may make will be challenged later, will be sufficient for them to agree. However, if the young person flatly refuses, in most cases no one can be required to undergo an assessment. In these circumstances, doctors should document the refusal in the medical record, make a decision about capacity based on the information they have available, and document the decision reached and the reasons for it. Where the question of capacity cannot be resolved on the basis of existing information, or if there are reasonable grounds to believe that the refusal of assessment results from coercion by a third party, legal advice should be sought.

## Key resources

BMA and The Law Society – Assessment of Mental Capacity (5th edition). Although this is based on the law in England and Wales, some of the practical information will still be useful for doctors practising in Northern Ireland.

BMA – Best interests decision making for adults who lack capacity. Although this is based on the law in England and Wales, some of the practical information will still be useful for doctors practising in Northern Ireland.

GMC – 0-18 years

Mental Health and Justice – Capacity Guide – Guidance for clinicians and social care professionals on the assessment of capacity – England and Wales only.

# 6 Best Interests

## What is meant by best interests?

All decisions taken on behalf of a 16 or 17-year-old who lacks capacity in England, Wales, and Northern Ireland must be taken in their best interests. The MCA in England and Wales provides a checklist of common factors that must be considered when making a best interests judgement. In addition, case law has established that when assessing an individual's best interests, decision makers must look at their welfare in the broadest sense. This must extend beyond medical factors to incorporate social and psychological dimensions of wellbeing. As part of the assessment process, the Supreme Court applying the English MCA has made it clear that the decision maker must make a reasonable effort to put themselves in the place of the patient and ask what their attitude to the proposed treatment would be. We consider that this approach applies equally to a decision maker applying the common law in Northern Ireland in relation to medical treatment. The focus should therefore be on determining what decision the 16 or 17-year-old would make if they had the capacity to choose.

## What should you consider when assessing best interests?

Lacking capacity to make a decision should not exclude a 16 or 17-year-old from participating in the decision-making process as far as possible. The decision maker must consider whether the person is likely to regain capacity and, if so, whether the decision can reasonably be left until they regain the capacity to make it. When determining whether an intervention would be in the best interests of a 16 or 17-year-old who lacks capacity, assumptions must not be made merely on the basis of the individual's age or appearance, their medical condition or any disability, or an aspect of their behaviour – this is the principle of equal consideration and non-discrimination. In most circumstances, it will be clear where the young person's best interests lie, and a decision as to care or treatment will not be challenging or time-consuming – but this is not always the case. Whether to provide analgesics for a 16 or 17-year-old in pain is likely to be a straightforward question, but a decision about whether to continue providing life-sustaining treatment is less so. Where a decision is likely to have grave consequences for a 16 or 17-year-old, it will require greater consideration, wider consultation with those close to the young person, and more detailed documented evidence about the decision reached and the reasons for it. Relevant factors to consider are likely to include (so far as they are reasonably ascertainable):

- the young person's past and present wishes and feelings;
- their wishes, beliefs, and values; and
- other factors the 16 or 17-year-old would have considered if able to do so, such as the effect of the decision on other people.

For significant decisions, a crucial part of best interests assessments involves discussion with those close to the young person who lacks capacity, including parents where it is practical or appropriate to do so, bearing in mind the duty of confidentiality (see section 9). The BMA has a best interests decision making toolkit which, although based on the legislation in England and Wales, contains a lot of practical information and guidance that may also be helpful for those practising in Northern Ireland (see key resources).

## What if there is disagreement over what is in a 16 or 17-year-old's best interests?

Where there is disagreement over what is in the best interests of a 16 or 17-year-old who lacks capacity, further discussion should take place and a second opinion should be offered. If agreement cannot be reached through discussion, it may be necessary to seek independent mediation, the views of a Clinical Ethics Committee (CEC), and/or legal advice. In the interim, in terms

6

of any treatment on which there is dispute, only that which is essential to preserve life or prevent serious deterioration should be provided (see section 8 on dispute resolution).

## Key resources

BMA – Best Interests decision-making for adults who lack capacity toolkit. Although this is based on the law in England and Wales, the practical information may also be useful for doctors working in Northern Ireland.

7

# Parental responsibility

## What is parental responsibility?

In England, Wales and Northern Ireland, parental responsibility is a legal term that includes the right to consent to treatment on behalf of a 16 or 17-year-old at their request (see section 2 on who can authorise treatment for a 16 or 17-year-old) or when they lack capacity (see sections 4 and 5 on capacity and incapacity, and assessing capacity), provided the treatment is in their best interests (see section 6 on best interests). The exception to this is a deprivation of liberty (DoL) (see section 10 on restraint and other restrictive practices).

## Do all parents have parental responsibility?

No. Not all parents have parental responsibility. In England, Wales, and Northern Ireland, a mother automatically acquires parental responsibility at birth.

A father acquires parental responsibility if he is married to the mother at the time of the young person's birth or subsequently. An unmarried father will acquire parental responsibility if he is recorded on the young person's birth certificate (at registration or upon re-registration).

For births registered outside the UK, the rules for the country where the young person resides apply.

## Can other people have parental responsibility?

An unmarried father who is not recorded on the young person's birth certificate, does not have parental responsibility even if he has lived with the mother for a long time. However, the father can acquire parental responsibility by way of a court registered parental responsibility agreement with the mother or by obtaining a parental responsibility order or a residence order from the courts. Married step-parents and registered civil partners can acquire parental responsibility in the same ways. Parental responsibility awarded by a court can only be removed by a court.

For a child born under a surrogacy arrangement, parental responsibility will lie with the surrogate mother and, if she is married or in a civil partnership, her husband or partner, until the intended parents either obtain a parental order from a court under the Human Fertilisation and Embryology Act 1990, or adopt the child.

Where the surrogate mother is not married or in a civil partnership, and the intended father's sperm was used, he can be named on the birth certificate and thereby obtain parental responsibility. If the intended father's sperm is not used, the surrogate can name either the intended mother or intended father as second parent, who will have parental responsibility jointly with the surrogate mother, provided:

- they were treated together in a UK clinic that is licensed by the Human Fertilisation and Embryology Authority (HFEA);
- they both signed the relevant form provided by the clinic, before the young person's conception; and
- they are both named on the birth certificate.

Other people can also acquire parental responsibility for a young person including:

- a guardian named in a will if no one with parental responsibility survives the person who wrote the will;
- a guardian appointed by a court;

7

– the adoptive parents where a young person is adopted; and
– a local authority, shared with anyone else with parental responsibility, while the young person is subject to a care or supervision order (foster parents rarely have parental responsibility).

### What if the parents are divorced?

Parents do not lose parental responsibility if they divorce, nor can a separated or divorced parent relinquish parental responsibility. This is true even if the parent without custody does not have contact with the young person and does not make any financial contribution.

### What is the role of parents who do not have parental responsibility?

Parents who do not have parental responsibility may also play an essential role in determining the best interests of a 16 or 17-year-old who lacks capacity and may have a right, under the Human Rights Act, to participate in treatment decisions for those under the age of 18.

### What happens if there is a disagreement between people with parental responsibility?

Generally, the law requires doctors to have consent from only one person to lawfully provide treatment. In practice, however, parents sometimes disagree, and doctors are reluctant to override a parent's strongly held views, particularly when it is not clear what is best for the young person. Discussions aimed at reaching a consensus should be attempted. If this fails, a decision must be made by the clinician in charge whether to go ahead despite the disagreement. The onus is then on the parent who refuses treatment to take steps to stop it.

### What if the parents are not communicating with each other?

There are occasions when parents do not communicate with each other, but both want to be involved in the young person's healthcare. For example, GPs may be asked to tell the parent, with whom a 16 or 17-year-old who lacks capacity is not resident, when the other parent brings them to the surgery. There is no requirement for GPs to agree to such requests, which could entail a lot of time and resources if the young person presents frequently, although doctors may agree to contact the absent parent under certain circumstances, for example if there is a serious concern.

### Key resources

GMC – 0-18 years

8

# Dispute resolution

## When do disputes occur?

Disputes can arise where a 16 or 17-year-old has capacity and refuses treatment that their parents and healthcare professionals believe is both necessary and in their best interests, or where the 16 or 17-year-old lacks capacity and the parents disagree with each other or oppose the treatment plan suggested by the healthcare team. It is also possible for the healthcare team not to agree about the right course of action.

## How should a dispute be approached?

Many disputes arise because of poor communication and all efforts should be made to avoid this. An independent second opinion, the view of a clinical ethics committee (CEC), and/or independent mediation may help to resolve some disagreements, but ultimately some may have to be resolved by the courts. Healthcare professionals must always focus on the overall best interests of the young person.

## When should legal advice be sought?

Legal advice should be sought swiftly when:

- a 16 or 17-year-old with capacity refuses an intervention or treatment that the healthcare team considers to be necessary to prolong life or prevent serious deterioration in their condition, and is in their best interests; or
- a 16 or 17-year-old lacks capacity and there is disagreement between those with parental responsibility and the healthcare team over the young person's best interests.

If agreement cannot be reached in a reasonable period, which will depend on the nature and likely course of the patient's condition, lawyers may advise that it is necessary to seek a court order. The 16 or 17-year-old, and where appropriate their parents, should be informed and told how to seek legal representation.

Legal advice should also be sought where:

- the proposed treatment or care is controversial or non-therapeutic (for example sterilisation, and live organ donation);
- the courts have stated that they need to review a particular decision;
- the treatment requires detention outside the provisions of mental health legislation;
- the young person is a ward of court, and the proposed step is important; or
- the proposed course of action might breach the young person's human rights under the Human Rights Act 1998.

## How can involving the courts help?

Going to court can be distressing for those concerned and it is essential that ongoing support is provided for the young person, and the healthcare team. There are great benefits, however, of a legal system that can give rulings very quickly when necessary. The law can provide a protective role for both the young person, and the healthcare team who treats them, where there is a disagreement that cannot be resolved.

## Can the courts insist on treatment?

In England, Wales, and Northern Ireland, a court can override a refusal of treatment where a 16 or 17-year-old has capacity, or where the 16 or 17-year-old lacks capacity and the parents refuse a particular treatment, and the healthcare professional is of the view that this is contrary to the young person's best interests. See, for example, a summary of the case of *NHS Trust v X (In the matter of X (A Child) (No 2))*.

8

The courts cannot, however, require doctors to treat contrary to their professional judgement.

## Key resources

GMC – 0-18 years

9

# Confidentiality and information sharing

## When is a duty of confidentiality owed to a 16 or 17-year-old who has capacity?

A duty of confidentiality is owed to all 16 or 17- year-olds. The duty owed is the same as that owed to an adult. As with adults, the duty of confidentiality is not absolute and confidential information can be disclosed when one of the following circumstances applies:

- consent;
- a legal requirement to disclose or the disclosure has statutory authorisation which has set aside the common law duty of confidentiality; or
- where there is an overriding public interest.

The BMA's *Confidentiality and health records toolkit* provides more detail on the latter two points (see key resources).

When disclosing confidential information healthcare professionals must:

- disclose only the minimum relevant information necessary;
- ensure the disclosure is to the appropriate authority;
- document the disclosure in the medical record;
- be prepared to justify their decisions to disclose (or not to disclose); and
- seek advice from the Caldicott Guardian, Data Protection Officer, or other appropriate senior person if there is uncertainty.

## Can a 16 or 17-year-old with capacity consent to, or refuse, the disclosure of their personal information?

Yes. 16 or 17-year-olds can give or withhold their consent to the release of information, and healthcare professionals should comply with such requests, unless there are convincing reasons to the contrary, for example where disclosure is justified in the public interest (for information about public interest disclosures, see the BMA's *Confidentiality and health records toolkit*). If the information is about particularly important or life-changing decisions, however, healthcare professionals should try to encourage the 16 or 17-year-old to share information with a parent or other adult.

## Can a parent or carer give, or withhold, consent to the disclosure of personal information about a 16 or 17-year-old who has capacity?

No. Where a 16 or 17-year-old has capacity no other person can consent to or refuse the disclosure of their personal health information.

## Is a duty of confidentiality owed to 16 or 17-year-olds who lack capacity?

Yes. Healthcare professionals owe the same duty of confidentiality to all their patients, whether or not they have capacity. Healthcare professionals may therefore usually only disclose information about a young person who lacks capacity where it is in the patient's best interests, or when one of the following circumstances applies:

- a legal requirement to disclose or the disclosure has statutory authorisation which has set aside the common law duty of confidentiality; or
- where there is an overriding public interest.

The BMA's *Confidentiality and health records toolkit* provides more detail on the latter two points (see key resources).

9

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- document the disclosure in the medical record;
- be prepared to justify their decisions to disclose (or not to disclose); and
- seek advice from the Caldicott Guardian, Data Protection Officer, or other appropriate senior person if there is uncertainty.

### Can someone with parental responsibility give, or withhold, consent to the disclosure of personal information about a 16 or 17-year-old who lacks capacity?

In England, Wales, and Northern Ireland, anyone with parental responsibility can give or withhold consent to the release of information where the young person lacks capacity. Where an individual who has parental responsibility refuses to share relevant information with other healthcare professionals or agencies, and the healthcare professional considers that it is not in the best interests of the young person, for example if it puts the young person at risk of significant harm, disclosure may take place in the public interest without consent.

### What if there are concerns a 16 or 17-year-old is at risk of abuse or neglect?

Where healthcare professionals have concerns about a 16 or 17-year-old who may be at serious risk of abuse or neglect, whether or not they lack capacity, these concerns must be acted upon, and information given promptly to an appropriate person or statutory body to prevent further harm (see section 13 on safeguarding). Young people may try to elicit a promise of confidentiality from adults to whom they disclose abuse. Doctors must avoid making promises of confidentiality that they cannot keep. Where doctors believe it is important that action is taken, they need to discuss disclosure with the young person, and if possible, they should be given sufficient time to come to a considered decision. If the young person cannot be persuaded to agree to voluntary disclosure, and there is an immediate need to disclose information to an outside agency, they should be told what action is to be taken unless doing so would expose the young person or others to increased risk of serious harm.

### Key resources

BMA – Confidentiality and health records toolkit.
BMA – Best interests decision making for adults who lack capacity toolkit. Although this is based on the legislation in England and Wales much of the practical information and guidance will also be helpful to doctors practising in Northern Ireland.

# 10 Restraint and other restrictive practices

## What is restraint, and when can it be used?

There may be occasions when healthcare professionals need to consider the use of restraint in treating a 16 or 17-year-old who lacks capacity. Restraint is the use or threat of force, to make someone do something they are resisting, or restricting a person's freedom of movement, whether they are resisting or not. The MCA in England and Wales only refers to restraint to prevent harm to the patient. Healthcare professionals in England and Wales have a common law right to use proportionate restraint to prevent the immediate risk of harm to others. In Northern Ireland, healthcare professionals have a common law right to use proportionate restraint to prevent the immediate risk of harm to the young person or others.

Further information about the use of restraint in England and Wales can be found in the BMA Mental Capacity Act England and Wales toolkit, and the MCA Code of Practice (see key resources). In Northern Ireland, any use of restrictive practices, including the use of restraint, should comply with the NI Department of Health's Regional policy on the use of restrictive practices in health and social care settings. Further information about the use of restraint in Northern Ireland can also be found in the BMA Mental Capacity in Northern Ireland toolkit (see key resources).

## What should a healthcare professional do if the restraint amounts to a deprivation of liberty in England, Wales and Northern Ireland?

Following the judgment of the Supreme Court in *Re D (A Child),* parental responsibility for a 16 or 17-year-old who lacks capacity does not extend to authorising a confinement of a young person in circumstances amounting to a deprivation of liberty (DoL) in England and Wales, and Northern Ireland. If restraint amounts to a deprivation of liberty, the required legal authority must therefore be in place for the action to be lawful.

In England and Wales, when a 16 or 17- year-old lacks capacity, a DoL can only be authorised by the Court of Protection, the inherent jurisdiction of the High Court, or under the Mental Health Act 1983. The deprivation of liberty safeguards contained in the MCA 2005 are not applicable to 16 and 17-year-olds. Decisions about whether a 16 or 17-year-old's care or treatment arrangements amount to a deprivation of liberty must be considered on a case-by-case basis. The 'acid test' has been defined as:

- lack of capacity to consent to the care/treatment;
- continuous supervision or control; and
- not being free to leave.

Examples of measures which can amount to a deprivation of liberty are:

- restraint, including sedation;
- control over assessments, treatment, contacts, and residence;
- the young person would be prevented from leaving if they made a meaningful attempt to do so;
- the young person is unable to maintain social contacts because of the restrictions placed on access to other people; and
- the young person loses autonomy because they are under continuous supervision and control.

In *Re D (A Child),* the Supreme Court held that 'the crux of the matter' when considering whether the confinement condition is met in relation to a person

10

aged under 18 is to ask whether 'the restrictions fall within normal parental control for a child of this age'. If they go beyond normal parental control, the confinement condition will be met, and the young person will be confined. Where there is doubt as to whether care or treatment amounts to a DoL, legal advice should be sought.

In Northern Ireland, the deprivation of liberty of a 16 or 17-year-old who lacks capacity can be authorised if it complies with the deprivation of liberty safeguards in the MCA (NI) and the DoLs Code of Practice 2019. Further information on care amounting to a DoL in Northern Ireland can be found in the Mental Capacity in Northern Ireland toolkit (see key resources).

## Key resources

BMA – Mental Capacity Act England and Wales toolkit
BMA – Mental Capacity in Northern Ireland toolkit
DHNI – Regional policy on the use of restrictive practices in health and social care settings
The Law Society (England and Wales) – Identifying a deprivation of liberty: a practical guide – Chapter 4: Children and young people under 18

11

# Sexual activity

## Can a young person aged 16 or 17- year- old consent to treatment associated with sexual activity?

As with other medical interventions, a 16 or 17-year-old with capacity may give valid consent to abortion, contraception, and treatment for a sexually transmitted infection. The courts have also confirmed that a parent's refusal to give consent for an abortion cannot override the consent of a young person with capacity.

If a 16 or 17-year-old lacks capacity, and it is in their best interests, a person with parental responsibility can legally give consent for the provision of contraception and abortion (provided the legal requirements of abortion legislation are met). If a young person lacks capacity to consent to the provision of contraception and the termination of pregnancy, this raises a question about the ability of the young person to consent to sexual intercourse. In cases of doubt, or where the provision of contraception will involve restraint or an invasive procedure, for example, insertion of an Intra Uterine Device (IUD), doctors should seek legal advice.

Where healthcare professionals believe that the 16 or 17-year-old may be subject to coercion or exploitation, safeguarding guidelines must be followed. Healthcare professionals with concerns should seek advice and help, anonymously if necessary, from colleagues with expertise in safeguarding, such as named and designated professionals (see section 13 on safeguarding).

## Does a healthcare professional need to inform the parents of a young person about their sexual activity?

No. All young people are entitled to have their confidentiality respected, unless there are very convincing reasons to the contrary, for example, if serious abuse is suspected (see section 9 on confidentiality and information sharing and section 13 on safeguarding).

## What if a healthcare professional disapproves of young people being sexually active?

Healthcare professionals must not allow any personal views held about a patient to prejudice their assessment of the patient's clinical needs, or delay or restrict the patient's access to care. Doctors should not impose their beliefs on patients. The GMC states in its guidance on 0-18 years:

'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' (paragraph 65).

## Key resources

GMC – 0-18 years
RCPCH – Safeguarding guidance for children and young people under 18 accessing early medical abortion services

12

# Female genital mutilation

## What is female genital mutilation (FGM)?

FGM is a collective term used for a range of practices involving the removal or alteration of parts of healthy female genitalia for non-therapeutic reasons. Different degrees of mutilation are practised by a variety of cultural groups in the UK. FGM has immediate risks, including severe pain, haemorrhage, tetanus and other infections, septicaemia, or even death. In the longer term, girls and women may experience problems with their sexual, reproductive, and general physical and psychological health. The risk of FGM may also give rise to legitimate grounds for an application for refugee or asylum status.

## Are there any considerations additional to the usual safeguarding measures?

FGM is illegal in England, Wales, and Northern Ireland under the Female Genital Mutilation Act 2003 (as amended by the Serious Crime Act 2015). If a 16 or 17-year-old is identified as being at risk of FGM, urgent safeguarding action must be taken (see section 13 on safeguarding). There is additional legislation and guidance specifically relating to FGM that doctors should be aware of (see key resources below). For example, there is a statutory duty in England and Wales to notify the police if a young woman or girl is aged under 18:

- informs a healthcare professional that FGM has been carried out on her; or
- a healthcare professional observes physical signs appearing to show FGM.

## Key resources

GMC – Protecting children and young people
Health Education England – FGM e-learning programme
RCGP – Female Genital Mutilation
RCOG – Female Genital Mutilation and its Management (Green-top Guideline No. 53)
RCPCH – Female Genital Mutilation Resources
HM Government England and Wales – Multi-agency statutory guidance on female genital mutilation
DHNI – Multi-agency practice guidelines: female genital mutilation

# 13 Safeguarding

For all young people aged 16 or 17 years old in the UK, the level of risk reduces due to their increasing maturity. However, where healthcare professionals have concerns about a 16 or 17-year-old who may be at risk of serious abuse or neglect, these concerns must be acted upon following local and national guidelines (see key resources). The best interests of the 16 or 17-year-old involved must always guide decision making. Paragraph 1 of the GMC's guidance *Protecting children and young people* outlines the following key principles for protecting children and young people:

a. 'All children and young people have a right to be protected from abuse and neglect – all doctors have a duty to act on any concerns they have about the safety or welfare of a child or young person.
b. All doctors must consider the needs and wellbeing of children and young people – this includes doctors who treat adult patients.
c. Children and young people are individuals with rights – doctors must not unfairly discriminate against a child or young person for any reason.
d. Children and young people have a right to be involved in their own care – this includes the right to receive information that is appropriate to their maturity and understanding, the right to be heard and the right to be involved in major decisions about them in line with their developing capacity (see the advice on assessing capacity in appendix 1 to this guidance).
e. Decisions made about children and young people must be made in their best interests – the factors to be considered when assessing best interests are set out in appendix 2.
f. Children, young people, and their families have a right to receive confidential medical care and advice – but this must not prevent doctors from sharing information if this is necessary to protect children and young people from abuse or neglect.
g. Decisions about child protection are best made with others – consulting with colleagues and other agencies that have appropriate expertise will protect and promote the best interests of children and young people.
h. Doctors must be competent and work within their competence to deal with child protection issues – doctors must keep up to date with best practice through training that is appropriate to their role. Doctors must get advice from a named or designated professional or a lead clinician or, if they are not available, an experienced colleague if they are not sure how to meet their responsibilities to children and young people'.

## Key resources

GMC – Protecting children and young people
GMC – 0-18 years
RCPCH intercollegiate document – Safeguarding Children and Young People: Roles and Competences for Health Care Staff
DFE – Working together to safeguard children Statutory guidance on inter-agency working to safeguard and promote the welfare of children
DFE – Child sexual exploitation Definition and a guide for practitioners
DFE – What to do if you're worried a child is being abused: advice for practitioners
NICE – Child maltreatment: when to suspect maltreatment in under 18s.
DHNI – Co-operating to Safeguard Children and Young People in Northern Ireland
Welsh government – Safeguarding children at risk of abuse or neglect

# 14 Compulsory treatment for a mental health condition

## When should mental health legislation be used?

In most cases, treatment and support for a 16 or 17-year-old's mental health condition is provided with consent. In some circumstances, however, mental health legislation can provide a legal structure for compulsory psychiatric care and treatment for a young person's mental health condition, irrespective of whether or not they retain formal decision-making capacity.

Compulsory treatment cannot be used to provide treatment for a physical illness unrelated to the mental health condition. Although, for some 16 or 17-year-olds, a severe mental illness is associated with a corollary lack of capacity, a mental health condition does not automatically diminish their legal capacity. Doctors who believe that the legislation may apply to one of their 16 or 17-year-old patients, but who are unfamiliar with the legislation, should seek expert advice.

## What legislation is applicable in England and Wales?

The Mental Health Act 1983 (as amended most recently by the Mental Health Act 2007) covers all 16 and 17-years olds. The Act contains some provisions and specific safeguards namely:

- 16 and 17-year-olds with capacity cannot have their consent or refusal to informal admission to hospital or registered establishment for treatment of a mental health condition overridden by those with parental responsibility;
- at least one of the people involved in the assessment on admission and treatment under the Act should be a clinician specialising in Child and Adolescent Mental Health Services (CAMHS). Where this is not possible, a CAMHS clinician should be consulted;
- electro-convulsive therapy (ECT) cannot be given without approval of a second opinion appointed doctor even if the 16 or 17-year-old consents to it unless it is an emergency; and
- young people detained under the Act must be referred after one year (as opposed to three for adults) for a tribunal hearing.

New legislation is anticipated following the independent review of the Mental Health Act. Details of any changes will be posted on the BMA website.

## What legislation is applicable in Northern Ireland?

The Mental Health (Northern Ireland) Order 1986 covers all 16 and 17-year-olds. There are no specific safeguards for 16 and 17-year-olds. New legislation combining both mental health and mental capacity law in Northern Ireland has been passed, but the provisions related to mental healthcare have not yet been implemented.

## Key resources

England and Wales: Department of Health – Code of Practice Mental Health Act 1983 – primarily chapter 19
Northen Ireland: Regulation and Quality Improvement Authority – Guidelines on the use of the Mental Health (Northern Ireland) Order 1986

# 15 Research

## Can 16 and 17-year-olds who have capacity participate in research?

Yes, as with adults, a 16 or 17-year-old with capacity can give their consent to research including research into a clinical trial of an investigational medicinal product (CTIMP). The involvement of those with parental responsibility is, however, usually encouraged, unless the 16 or 17-year-old objects.

## 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.

## Can young people aged 16 and 17 years old who lack capacity participate in research?

Where invasive research does not meet the criteria for a CTIMP, it may be lawful under the MCA to involve 16 and 17-year-olds in England and Wales who lack capacity, provided it is related to the condition or treatment for the condition from which they are suffering. Research must be approved by an appropriately established research ethics committee, or, in Wales, its equivalent. It must not be possible to conduct the research with individuals who have the capacity to consent. Further information involving research on patients who lack capacity in England and Wales can be found in the Mental Capacity Act England and Wales toolkit (see key resources).

In Northern Ireland, under the MCA(NI) and the Mental Capacity (Research) Regulations (Northern Ireland) 2019, it is lawful to involve 16 and 17-year-olds who lack capacity in research in some circumstances. In order for research involving patients who lack capacity to be lawful, the interests of the patient must at all times be assumed to outweigh any benefits to science and society. Further information involving research on patients who lack capacity in Northern Ireland can be found in the Mental capacity in Northern Ireland toolkit (see key resources)

15

## Key resources

BMA – Consent and refusal by adults with decision-making capacity
BMA – Mental Capacity Act England and Wales toolkit
BMA – Mental Capacity in Northern Ireland toolkit
Health Research Authority – Research involving children

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