

# **Children and young people toolkit**

A toolkit for doctors



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## About this toolkit

Questions about children and young people are a significant area of ethical enquiry for the British Medical Association (BMA) with doctors facing ever more complex dilemmas. High-profile cases around disagreements as to what is in a child's best interests, child protection, access to sexual health services, trans healthcare and the vaccination of children highlight the sensitivity and difficulties doctors face in this area. Doctors need to know when a young person is competent and what this means in terms of their ability to consent and refuse healthcare, and what limits are placed on those with parental responsibility.

The purpose of this toolkit is not to provide definitive answers for every situation but to identify the key factors that need to be considered when such decisions are made, and signpost other key documents. The toolkit has sections about specific areas relating to the examination and treatment of people in England, Wales and Northern Ireland who are aged under 18, and in Scotland under 16. There are separate sections identifying factors to be considered when assessing competence and determining 'best interests,' and sensitive areas including child protection and access to sexual health services. All sections refer to useful guidance from bodies such as the General Medical Council (GMC), BMA and health departments, which should be used in conjunction with the guidance. In addition, the medical defence bodies and many of the royal colleges produce specific advice for their members. Section 19 lists contact details for organisations from whom further advice can be obtained.

The toolkit is available on the BMA's website and individual trusts, health boards, medical schools, and individual health professionals may download and adapt it to suit their requirements. There are no copyright restrictions on this toolkit – please feel free to make multiple 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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This is the second edition of the BMA's Children and young people toolkit. Information about developments since its publication may be obtained from the BMA's website or by contacting the BMA medical ethics and human rights department.

# 2

## Basic principles

Basic principles have been established regarding the way the treatment of children and young people should be approached. These reflect standards of good practice, which are underpinned by domestic and international law.

The welfare of children and young people is the paramount consideration in decisions about their care. Children and young people can expect:

- to be kept as fully informed as they wish, and as is possible, about their care and treatment
- health professionals to act as their advocates
- to have their views and wishes sought and considered as part of promoting their welfare in the widest sense
- to be the individual who consents to treatment when they are competent, and wish to do so
- to be encouraged to take decisions in collaboration with other family members, especially parents, if this is feasible
- that information provided will remain confidential unless there are exceptional reasons that require confidentiality to be breached.

Doctors caring for children and young people have a number of ethical and legal obligations with which they should be familiar and that are outlined in best practice guidance, statute, and case law. For example, the Gillick case, Children Acts 1989 and 2004, the Children (Scotland) Act 1995, Children (Northern Ireland) Order 1995, Age of Legal Capacity (Scotland) Act 1991, Mental Capacity Act 2005 (England & Wales), Family Law Reform Act 1969, Human Rights Act 1998, and the United Nations Convention on the Rights of the Child.

### Key resources

GMC – 0-18 years: guidance for all doctors. Available at:

[www.gmc-uk.org](http://www.gmc-uk.org)

Royal College of Paediatrics and Child Health and partnerships organisations – Supporting LGBTQ+ children and young people - principle statement. Available at: [www.rcpch.ac.uk](http://www.rcpch.ac.uk)

# 3

## Assessing competence

### Can competence ever be presumed?

Yes. All people aged 16 and over are presumed in law to be competent to give their consent to medical treatment in England, Scotland, Wales, and Northern Ireland (see section 8 for more information on 16- to 17-year-olds who lack mental capacity).

### Can a young person be competent under the age of 16?

Yes, but this needs to be assessed in each case on an ongoing basis. Doctors should aim to involve all children and young people in decisions relating to their medical treatment. It is important to recognise when a young person can make a valid choice about a proposed medical intervention or disclosure of personal medical data and is therefore competent to make a personal decision. Doctors should not judge the ability of a particular child or young person solely based on their age.

For a young person under the age of 16 to be competent, they should have:

- the ability to understand that there is a choice and that choices have consequences
- the ability to weigh the information and arrive at a decision
- a willingness to make a choice (including the choice that someone else should make the decision)
- an understanding of the nature and purpose of the proposed intervention
- an understanding of the proposed intervention's risks and side effects
- an understanding of the alternatives to the proposed intervention, and the risks attached to them
- freedom from undue pressure.

Competent under 16-year-olds are sometimes referred to as being 'Gillick competent'. In England, Wales and Northern Ireland, children aged 12 or over are generally expected to have the competence to give or withhold their consent to the release of information. In Scotland, anyone aged 12 or over is legally presumed to have such competence (see section 11 on confidentiality).

### Who should assess competence?

Health professionals who assess competence need to be skilled and experienced in discussions with young patients and eliciting their views. The treating doctor may be the most appropriate person, but other members of the healthcare team who have a close rapport with the patient may also have valuable contributions to make. The health professional providing the treatment must be satisfied that the patient is competent before providing the treatment if they are relying on their consent.

### How can competence be promoted?

When assessing a child's competence, it is important to explain the issues in a way that is suitable for their age. A young patient may be competent to make some, but not all, decisions and clinical staff should promote an environment in which young patients can engage in decisions as much as they are able. The child or young person's ability to play a full part in decision-making can be enhanced by allowing time for discussion.

#### Key resource:

GMC – 0-18 years: guidance for all doctors. Available at:  
[www.gmc-uk.org](http://www.gmc-uk.org)

# 4

## Parental responsibility

### Who can consent on behalf of a baby or child who lacks competence?

Someone with parental responsibility, provided the decision is in the best interests of the child.

### Do all parents have parental responsibility?

No. Not all parents have parental responsibility. In the UK, a mother automatically acquires parental responsibility at birth. However, the acquisition of parental responsibility by a father varies according to where and when the child's birth was registered.

### When does a father acquire parental responsibility?

- For births registered in Northern Ireland: a father acquires parental responsibility if he is married to the mother at the time of the child's birth or subsequently. An unmarried father will acquire parental responsibility if he is recorded on the child's birth certificate (at registration or upon re-registration).
- For births registered in England or Wales: a father acquires parental responsibility if he is married to the mother at the time of the child's birth or subsequently. An unmarried father will acquire parental responsibility if he is recorded on the child's birth certificate (at registration or upon re-registration) from 1 December 2003 in England or Wales.
- For births registered in Scotland: a father acquires parental responsibility if he is married to the mother at the time of the child's conception or subsequently. An unmarried father will acquire parental responsibility if he is recorded on the child's birth certificate (at registration or upon re-registration) from 4 May 2006.
- For births registered outside the UK: the above rules for the country where the child resides apply.

### Can other people have parental responsibility?

An unmarried father whose child's birth was registered before the dates mentioned above, or afterwards if he is not recorded on the child'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 if she is married, or in a civil partnership and her husband until the intended parents either (a) obtain a parental order from a court under the Human Fertilisation and Embryology Act 1990, or (b) adopt the child.

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Where the surrogate mother is not married or in a civil partnership, the intended mother or non-biological intended father in the surrogacy arrangement 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 Embryology Authority (HFEA)
- they both signed the relevant form provided by the clinic, before the child's conception
- they are both named on the birth certificate.
- 

Other people can also acquire parental responsibility for a child 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
- the adoptive parents when a child is adopted
- a local authority, shared with anyone else with parental responsibility, while the child is subject to a care or supervision order (foster parents rarely have parental responsibility).

Parents are also entitled to authorise another person to take over particular responsibilities. For example, a parent may consent for another person to take the child for a vaccination, or to collect medication.

## **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 child and does not make any financial contribution.

## **Until what age can parental responsibility be exercised?**

In England, Wales and Northern Ireland, parental responsibilities may be exercised until a young person reaches 18 years. In Scotland, only the aspect of parental responsibilities concerned with the giving of 'guidance' endures until 18 years – guidance meaning the provision of advice. The rest is lost when the young person reaches 16 years, although some may be lost before this if the child attains the legal capacity to act on their own behalf.

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

It should be noted that parents who do not have parental responsibility may also play an essential role in determining best interests and may have a right, under the Human Rights Act, to participate in treatment decisions.

## **Are there any limits to what people with parental responsibility can consent to?**

The moral authority behind parental responsibility depends on the entirely reasonable supposition that parents will act in the best interests of their children. If it appears, however, that parents are following a course of action which is contrary to their child's interests, their decisions can be challenged. Where doctors believe that parental decisions are not in the best interests of the child, it may be necessary to seek a view from the courts, whilst providing only emergency treatment that is essential to preserve life or prevent serious deterioration.

# 4

## **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 child. 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. If the dispute is over an irreversible, controversial, elective procedure (eg, male infant circumcision for religious purposes, or vaccination) when it is known one of the parents objects, doctors must not proceed without the authority of a court (see section 9 on disputes).

## **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 their child's healthcare. For example, GPs are frequently asked to tell the parent with whom the child is not resident when the other parent brings the child 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 child presents frequently. It is clearly better if parents can communicate with each other about their child's health, although doctors may agree to contact the absent parent under certain circumstances, for example if there is a serious concern.

Where a procedure is controversial, eg, non-therapeutic male circumcision, if a child presents with only one parent the doctor must contact the other parent to seek consent.

### **Key resource**

BMA – Non-therapeutic male circumcision (NTMC) of children – practical guidance for doctors. Available at: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)



# 5

## Consent and refusal

### Who can consent to a child or young person's treatment?

The following are legally entitled to give consent to medical treatment of a child or young person:

- a competent child or young person (see section 3 on assessing competence)
- a parent or other person or agency with parental responsibility where the decision is in the best interests of the child (see sections 4 and 6 on parental responsibility and best interests)
- a court
- in Scotland, an appointed proxy where patients are over 16 and unable to make decisions themselves (see section 8 on 16- to 17-year-olds who lack mental capacity)
- a person caring for a child eg, a grandparent or childminder, may do what is reasonable in the circumstances to safeguard or promote the child's welfare (see section 4 on parental responsibility). In Scotland, the primacy of any known wishes of the parents in these situations has statutory force. If a carer brings a child for treatment, steps should be taken to ascertain the parents' views, and if there is doubt about authority to proceed, doctors should seek legal advice.

### Are there any procedures a young person over 16 years old is not presumed to be competent to consent to?

In England, Wales and Northern Ireland there are some rare procedures, for example live organ donation, some non-therapeutic procedures and research, where the presumption of competence for 16- to 17-year-olds does not apply. A 16- to 17-year-old is only considered competent if Gillick competent (see section 3 on assessing competence). These exceptions do not apply in Scotland where a young person over the age of 16 is treated as an adult.

### If a competent young person can consent to treatment, does it also follow that they can refuse treatment?

No, not always. In England, Wales and Northern Ireland, a competent refusal by a patient under 18 can be overruled by a court or by a person with parental responsibility. Health professionals faced with an informed refusal of a treatment they believe to be in the patient's best interests should take legal advice, for example, a refusal of lifesaving treatment or treatment that would prevent permanent injury. The reasons why the child or young person has refused should be discussed beforehand to ensure the refusal is not based on inaccurate perceptions. In Scotland, it seems likely from current case law and statute that a competent refusal cannot be overridden by any other person, carer, or court, even if that treatment is necessary to save or prolong life. This matter is not beyond doubt and legal advice should be sought when such situations arise.

The same principles apply to advance decisions to refuse treatment.

In UK jurisdictions where a young person's contemporaneous refusal of treatment may not be determinative, it follows that advance decisions to refuse treatment made by young people cannot be legally binding on health professionals.

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However, before seeking consent from either a person with parental responsibility or a court, doctors must look at whether the harms associated with imposing treatment on a patient who refuses, competently or not, 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 patient. As much time as is practicable should be taken for discussion, and treatment delayed if that is possible without jeopardising its likely success.

## **Can a person with parental responsibility refuse treatment?**

Refusal by those with parental responsibility is not necessarily determinative if treatment is considered in the child or young person's best interests, a competent young person consents to treatment, or the court approves treatment. For example, where children need blood products to prevent death or serious deterioration, a refusal by a parent who is a Jehovah's Witness is unlikely to be binding on doctors.

## **In an emergency, where consent is unavailable, on what basis can a child or young person be treated?**

In an emergency, where consent is unavailable, for example, when the patient is unable to communicate their wishes and where nobody with parental responsibility is available, it is legally and ethically appropriate for health professionals to proceed with the treatment necessary to preserve the life, health, or wellbeing of the patient. 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 child and/or family is known to object eg, the administration of blood to a Jehovah's Witness, viable alternatives should be explored if time allows. In extreme situations, however, health professionals are advised to take all essential steps to stabilise the patient. Legal advice may be needed once emergency action has been taken.

### **Key resource**

GMC – 0-18 years: guidance for all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)

# 6

## Best interests

### Who decides what is in a child or young person's 'best interests'?

Where a child lacks competence there is a presumption that the child's parents have the child's best interests at heart. This is not always the case, however, and doctors should be alert to situations in which parents' decisions appear to be contrary to their child's interests.

Where a young person is competent, the young person's views on what would be in their best interests are of importance to the decision-making process, although they may not always be determinative.

### What needs to be considered when assessing a child's or young person's best interests?

A best interests judgement is as objective a test as possible of what would be in the child's actual best interests, considering all relevant factors. It is customary to assume that a person's interests are usually best served by measures that offer the hope of prolonging life or preventing damage to health, but this is not always the case. Several factors should be considered, including:

- the patient's wishes, feelings, and values (where these can be ascertained)
- the patient's ability to understand what is proposed and weigh up the alternatives
- the patient's potential to participate more in the decision, if provided with additional support or explanations
- the patient's physical and emotional needs
- clinical judgment about the effectiveness of the proposed treatment, and particularly other options
- where there is more than one option, which option is least restrictive of the patient's future choices
- the likelihood and extent of any improvement in the patient's condition if treatment is provided
- risks and side effects of the treatment or non-treatment
- the views of parents and others who are close to the patient about what is likely to benefit the patient
- relevant information about the patient's religious or cultural background
- the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare.

### What if there is disagreement over what is in a child or young person's best interests?

Where there is disagreement over what is in the best interests of a child or young person, further discussion should take place and a second opinion should be offered, but it may be necessary to seek mediation, the views of a Clinical Ethics Committee (CEC), and legal advice. In the interim, only emergency treatment that is essential to preserve life or prevent serious deterioration should be provided (see sections 4 and 9 on parental responsibility and disputes).

#### Key resource

GMC – 0-18 years: guidance for all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)



## Unaccompanied minors

### Can children or young people make appointments for themselves?

Healthcare staff should not prohibit children and young people from making appointments and seeing a doctor without an accompanying adult. Although there are circumstances in which it is reasonable for doctors to want a parent present eg, because the child has a serious condition and needs help in complying with a treatment regime, a rule prohibiting young patients attending alone is not good practice and could lead to a complaint against the doctor. Establishing a trusting relationship between the patient and doctor at this stage will do more to promote health than if doctors refuse to see young patients without involving their parents.

Some doctors may be anxious about seeing young patients, especially in very sensitive or complex situations, without any input from an appropriate adult. The possible provision of family or parental support in these circumstances needs to be at least raised in the consultation, even though patients may reject the notion for various reasons, and their views then need to be respected.

### Is there a minimum age for consultations?

There is no reason why a patient of any age who is competent to make a request should not be able to ask to see a doctor in private. Doctors too may want to ask to see a patient alone. If, for example, a doctor suspects that a child is experiencing any form of child abuse, neglect or bullying, it may be appropriate to talk to the child privately (see section 15 on child protection).

### What if a child or young person fails to collect test results?

Where possible, health professionals should arrange in advance how competent children and young people will collect test results, and what should happen if they fail to collect them. If a prior arrangement has not been agreed, doctors should examine all reasonable options, including writing to or telephoning the patient, with due regard to confidentiality. If the young person lives with their parents and does not want the parents to know of the health interaction this should be borne in mind when considering the best way of contacting the patient.

### Should a chaperone always be offered when a child or young person is unaccompanied?

A parent or carer often acts as a chaperone for children or young people, but in the case of unaccompanied children or young people, they may be unaccompanied because they do not wish a parent or carer to be present. In these cases, the GMC states: 'you should think carefully about the effect the presence of a chaperone can have. Their presence can deter young people from being frank and from asking for help' (GMC – 0-18 years: guidance for all doctors, paragraph 15).

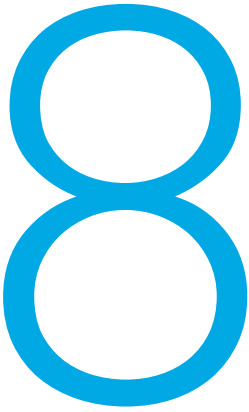
If a doctor needs to perform an intimate examination, however, the GMC's general advice is that wherever possible, a chaperone should be offered. If either the doctor or the patient does not wish the examination to proceed without a chaperone present, or if either is uncomfortable with the choice of chaperone, the doctor may offer to delay the examination to a later date when a chaperone (or an alternative chaperone) will be available, if this is compatible with the patient's best interests. If the patient does not want a chaperone, the doctor should record that the offer was made and declined.

#### Key resources

GMC – Intimate examinations and chaperones. Available at:

[www.gmc-uk.org](http://www.gmc-uk.org)

GMC – 0-18 years: guidance for all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)



## 16- to 17-year-olds who lack mental capacity

There may be occasions when a 16- to 17-year-old, who would usually be presumed to be competent to make decisions, may lack capacity. In these circumstances, doctors are advised to look at more detailed guidance on mental capacity and they may need to seek expert advice.

### On what basis can decisions be made for 16- to 17-year-olds who lack capacity?

In England and Wales, most of the Mental Capacity Act 2005 applies to 16- to 17-year-olds who lack capacity because of an impairment of, or a disturbance in the functioning of, the mind or brain. At the heart of the Act lies the principle that any decision or action taken must be in the best interests of the 16- to 17-year-old who lacks capacity.

There are some provisions in the Act that do not apply to 16- to 17-year-olds, namely:

- they cannot make a legally binding Lasting Power of Attorney (LPA)
- they cannot make an advance decision to refuse medical treatment
- the Court of Protection cannot make a statutory will.

In Scotland, the Adults with Incapacity (Scotland) Act 2000 sets out the framework for regulating interventions in the affairs of adults (people over 16) who have impaired capacity. It allows people over the age of 16 who have the capacity to appoint a welfare attorney to make health and personal welfare decisions once capacity is lost. The Court of Session may also appoint a deputy to make these decisions.

In Northern Ireland, decision-making is governed by the common law. The GMC advises that in Northern Ireland 'treatment can be provided in the young person's best interests if a parent cannot be contacted, although you should seek legal advice about applying for court approval for significant (other than emergency) interventions' (GMC – 0-18 years, paragraph 28c).

New legislation combining both mental health and mental capacity law in Northern Ireland has been passed but has not yet been implemented. Details of any changes will be posted on the BMA website at [www.bma.org.uk](http://www.bma.org.uk)

#### Key resources

##### England and Wales:

BMA – Mental Capacity Act toolkit. Available at:

[www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

##### Scotland and Northern Ireland:

BMA – Adults with incapacity in Scotland and Northern Ireland. Available at: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

# 9

## Disputes

### When do disputes occur?

Ideally, medical decisions are made in partnership between the patient, the family, and the health team, with the parental role gradually reducing as the child develops in maturity. Disputes arise, however, where there is a difference of opinion as to what is in a child or young person's best interests. For example, there could be a disagreement between a competent young person and their parents, the parents may disagree with each other, or the family may oppose the treatment plan suggested by the health team. See *Yates & Gard v Great Ormond Street Hospital for Children NHS Foundation Trust & Anor* (Rev 1) [2017] EWCA Civ 410 (23 May 2017); a summary of this case is available at: <https://sintons.co.uk/news/legal-update-case-charlie-gard-medical-treatment-decisions-limits-parental-autonomy>

### 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 mediation may help to resolve some disagreements, but ultimately some may have to be resolved by the courts. Health professionals must always focus on the overall best interests of the child or young person.

### When should legal advice be sought?

Legal advice should be sought swiftly when:

- agreement over how to proceed cannot be reached (for example where consent is refused by the holders of parental responsibility)
- a competent young person refuses an intervention or invasive treatment that the healthcare team considers necessary
- administering treatment against the wishes of a competent young person would require the use of restraint or force
- it is not clear whether the people with parental responsibility are acting in the best interests of the child
- the proposed care is beyond the scope of parental consent because it is controversial or non-therapeutic (for example sterilisation, organ donation and non-therapeutic male circumcision if parents disagree)
- the courts have stated that they need to review a particular decision
- the treatment requires detention outside the provisions of mental health legislation
- the people with parental responsibility lack the competence to make the decision
- the child is a ward of Court, and the proposed step is important
- the proposed course of action might breach a person's human rights under the Human Rights Act 1998.

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. Parents, and where appropriate, the patient, should be informed and told how to seek legal representation.

### 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 child, the parents, other relatives and carers, 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 patients and the healthcare team who treats them and where there is a disagreement that cannot be resolved.



### Can the courts insist on treatment?

In England, Wales and Northern Ireland the courts have the power to give consent to treatment on behalf of competent and incompetent patients aged under 18. A court can override a child's refusal or parents' refusal of a particular treatment if there is evidence that it would be in the child or young person's best interests. See *A NHS Trust v X (In the Matter of X (A Child) (No 2) [2021] EWHC 65 (FAM)*; a summary of this case is available at: [https://www.39essex.com/cop\\_cases/a-nhs-trust-v-x](https://www.39essex.com/cop_cases/a-nhs-trust-v-x)

In Scotland, the courts have the same powers to give consent to treatment on behalf of people aged under 16 when they are not competent to give valid consent for themselves. It is unclear whether a Scottish court may override the decision of a child if the medical practitioner believes the child is competent, although it is thought that this is unlikely. Legal advice should therefore be sought.

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

#### Key resources

GMC – 0-18 years: guidance for all doctors. Available at:

[www.gmc-uk.org](http://www.gmc-uk.org)

BMA – Non-therapeutic male circumcision (NTMC) of children - practical guidance for doctors. Available at: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

# 10

## Use of restraint when providing treatment

### Can doctors restrain children or young people to provide treatment against their wishes?

Once a decision has been made that it is lawful and ethically acceptable to override a refusal of treatment (see section 5 on consent and refusal) in principle there cannot be an absolute prohibition on the use of force to carry it out. However, doctors must look at the patient's overall interests, and whether imposing treatment is a proportionate interference given the expected benefits.

### What factors should be taken into account when considering the use of restraint?

Doctors should consider if imposing treatment could damage the young person's current and future relationships with healthcare providers and undermine trust in the medical profession. It is important for young people to understand that restraint of any form to provide treatment is used only as a last resort and not until other options for treatment have been explored. The child and the family must be offered continual support and information throughout the treatment period.

If, after spending as much time as is practicable, it is impossible to persuade a child to cooperate with essential treatment, the clinician in charge of the patient's care may decide that restraint is appropriate.

The following points are relevant to any action taken:

- restraint should be used only when it is necessary to give essential treatment or to prevent a child from significantly injuring themselves or others
- the effect should be to provide an overall benefit to the child, and in some cases, the harms associated with the use of restraint may outweigh the benefits expected from treatment
- restraint is an act of care and control, not punishment, and should be administered with due respect
- unless life-prolonging or other crucial treatment is immediately necessary, legal advice should be sought when treatment involves restraint or detention to override the views of a competent young person, even if the law allows doctors to proceed with parental consent
- all steps should be taken to anticipate the need for restraint and to prepare the child, their family, and staff
- wherever possible, the members of the healthcare team involved should have an established relationship with the child and should explain what is being done and why
- treatment plans should include safeguards to ensure that restraint is the minimum necessary, that it is for the minimum period necessary to achieve the clinical aim, and that both the child and the parents have been informed of what will happen and why restraint is necessary
- restraint should usually be used only in the presence of other staff, who can act as assistants and witnesses
- any use of restraint should be recorded in the medical records.



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## **Who is responsible for the decision to use restraint?**

Members of the healthcare team should be allowed to express their views and to participate in decision-making, although ultimate responsibility rests with the clinician in charge of care. All staff require support and must not be asked to be involved in restraining a child without proper training.

## **Can children and young people be detained to provide medical treatment?**

Detaining children to provide medical treatment raises serious legal issues. Legal advice is essential before children are detained outside the provisions of mental health legislation, and court approval will be necessary. A court asked to rule on such an issue is required to have regard for the young person's rights under the Human Rights Act 1998 and whether, in the circumstances, detention is compatible with these. For example, the right not to be subjected to inhuman or degrading treatment (Article 3), the right to liberty and security (Article 5), and the right to a fair hearing (Article 6).



## Confidentiality

### When is a duty of confidentiality owed to a child or young person?

A duty of confidentiality is owed to all children and young people. 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 (see section 5 on consent and refusal)
- a legal requirement to disclose or the disclosure has statutory authorisation which has set aside the common law duty of confidentiality
- where there is an overriding public interest.

In addition to the specific circumstances outlined in this toolkit that relate only to children and young people, the BMA's confidentiality toolkit provides more detail on the latter two. The toolkit is available at: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

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)
- seek advice from the Caldicott Guardian, Data Protection Officer, or other appropriate senior person if there is uncertainty.

### When is a young person competent to consent to the disclosure of their personal information?

In Scotland, anyone aged 12 or over is legally presumed to have such competence. In England, Wales and Northern Ireland it is also reasonable to presume that children who are aged 12 or over have the competence to give or withhold their consent to the release of information.

Younger children may also be competent to make decisions regarding the control of their health information (see section 3 on assessing competence). Health professionals should, unless there are convincing reasons to the contrary, eg. abuse is suspected, respect the child's wishes if they do not want parents or guardians to know about all or some aspects of their healthcare (see section 15 on child protection). However, every reasonable effort must be made to persuade the child to involve parents or guardians particularly for important or life-changing decisions.

### Are there limits to confidentiality if a child lacks competence?

Occasionally, children who lack competence seek or receive healthcare without their parents or guardians being present. They may lack the competence to give consent to treatment, and the disclosure of information (see section 13, for example, on sexual activity). In these circumstances, confidentiality should usually be respected if they share information on the understanding that the information will not be disclosed to parents or guardians, or indeed to any third party. Parental involvement, however, should be encouraged, unless there are very convincing reasons to the contrary.



There are, however, exceptions to this. For example, when not sharing the information puts the child, or others, at risk of significant harm (see, for example, section 15 on child protection). GMC guidance also states: 'You should usually try to persuade the child to involve a parent in such circumstances. If they refuse and you consider it is necessary in the child's best interests for the information to be shared. For example, to enable a parent to make an important decision, or to provide proper care for the child, you can disclose information to parents or appropriate authorities' (GMC – 0-18 years: guidance for all doctors, paragraph 51).

Where a health professional decides to disclose information to a third party against a child's wishes, the child should generally be told before the information is disclosed. The discussion with the child and the reasons for disclosure should be documented in the child's record.

### **Can someone with parental responsibility refuse disclosure of a child or young person's personal information?**

Anyone with parental responsibility can give or withhold consent to the release of information where the child lacks competence. Where an individual who has parental responsibility refuses to share relevant information with other health professionals or agencies, and the health professional considers that it is not in the best interests of the child, for example, it puts the child at risk of significant harm disclosure may take place in the public interest without consent (see sections 6 and 15 on best interests and child protection). Parents should usually be informed of the disclosure, the reasons for it, and the information that will be provided in advance of disclosure.

### **What if there are concerns a child or young person is at risk of abuse or neglect?**

Where health professionals have concerns about a child or young person who may be at risk of abuse or neglect, these concerns must be acted upon, and information given promptly to an appropriate person or statutory body to prevent further harm (see section 15 on child protection).

Children and young people may try and 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 child, and if possible, the child should be given sufficient time to come to a considered decision. If the child 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 child or others to increased risk of serious harm.

### **Who can access a child or young person's health record?**

Competent children and young people may apply for access to their records or may authorise others to do so on their behalf. Competent patients do not need to give reasons as to why they wish to access their records. If a child lacks competence the GMC advises that: 'In any event you should usually let children access their own health records. But they should not be given access to information that would cause them serious harm or any information about another person without the other person's consent.'



Anyone with parental responsibility may usually exercise their child's statutory right to apply for access to the child's health records. If the child is capable of giving consent, access may only be given with their consent. It may be necessary to discuss parental access alone with children if there is a suspicion that they are under pressure to agree. For example, the young person may not wish a parent to know about a request for contraceptive advice. If a child lacks the competence to understand the nature of an application but access would be in their best interests, it should be granted. Parental access must not be given where it conflicts with the child's best interests.

Where parents are separated, and both have parental responsibility, and one of them exercises their child's right to access the medical record, doctors are under no obligation to inform the other parent, although they may consider doing so if they believe it to be in the child's best interests. It is advisable to make a note of when, and by whom the record is accessed.

#### **Key resources**

BMA – Access to health records. Available at: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

BMA – Confidentiality toolkit. Available at: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

GMC – 0-18 years: guidance for all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)

GMC – Protecting children and young people: The responsibilities of all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)

# 12

## Vaccination

### Who can consent to vaccination?

A person aged 16 or 17, or a Gillick competent child, can consent to vaccination. Where someone aged 16 or 17, or who is Gillick competent, consents to vaccination, a person with parental responsibility cannot override that consent. If a person aged 16 or 17 or a Gillick competent child refuses treatment, that refusal should be accepted. For infants and young children not competent to give or withhold consent, consent can be given by a person with parental responsibility (see section 4 on parental responsibility).

### What if parents with parental responsibility disagree?

In England and Wales, the Department of Health 'Immunisation against Infectious Disease' (known as the Green Book), advises that vaccination should not be carried out unless both people with parental responsibility can agree to vaccination, or there is a specific court approval that the vaccination is in the best interests of the child (see sections 6 and 9 and best interests and disputes). This is likely to be the same in Scotland and Northern Ireland.

### Who should be present at the vaccination?

A person aged 16 or 17, or a Gillick competent child, can attend vaccination on their own. For infants or children who are not competent, the person with parental responsibility does not need to be present at the time of the vaccination; they may be brought for vaccination by a person without parental responsibility, eg, a grandparent or childminder. There is no requirement for such arrangements to be made in writing. However, the health professional needs to be satisfied that the person with parental responsibility has consented in advance to the vaccination and that they have asked the other person to take the child to the appointment, to consider any further information given by the health professional, and to confirm agreement to vaccination.

# 13

## Sexual activity

### Can a young person consent to treatment associated with sexual activity?

As with other medical interventions, a competent young person may give valid consent to abortion, contraception and treatment for a sexually transmitted infection, regardless of age or parental involvement, although every reasonable effort must be made to persuade the child to involve their parents or guardians. The courts have also confirmed that a parent's refusal to give consent for an abortion cannot override the consent of a competent young person. With respect to providing contraceptives, doctors should take into account:

- whether the patient is likely to have sexual intercourse without contraception
- whether the patient's physical and/or mental health is likely to suffer if the patient does not receive contraceptive advice or supplies
- whether the patient's best interests would require the provision of contraceptive advice or methods or both without parental consent.

Sexual activity in someone under the age of 13 will *always* be a cause for concern (see later question). The need to share information without consent to protect the young person must be balanced against the need to provide a service that encourages young people to seek help when they need it.

Where health professionals believe that children may be subject to coercion or exploitation, existing child protection guidelines must be followed. Health professionals with concerns should seek advice and help, anonymously if necessary, from colleagues with expertise in child protection, such as named and designated professionals (see section 15 on child protection).

### What if the young person lacks competence?

If a young person lacks competence, 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 competence to consent to the provision of contraceptives for 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, eg insertion of an IUD, doctors should seek legal advice. If there are concerns that a child is being sexually abused, doctors should follow child protection guidelines.

### Does a doctor need to inform the police or social services of all underage sexual activity?

No, only when there are concerns that the young person is being abused (see section 14 on some exceptions in Northern Ireland). The GMC states: 'You should usually share information about sexual activity involving children under 13, who are considered in law to be unable to consent. You should discuss a decision not to disclose with a named or designated doctor for child protection and record your decision and the reasons for it' (GMC – 0-18 years: guidance for all doctors, paragraph 60). While reporting to social services or the police should always be considered when the individual is very young, health professionals are obliged to act in the best interests of the patient, and this requires flexibility. Where a health professional decides to disclose information to a third party against a child's wishes, the child should generally be told before disclosing the information. The discussion with the patient and the reasons for disclosure should also be documented in the patient's record.

# 13

## **Does a doctor need to inform the parents of a young person?**

In most cases, no. All children are entitled to have their confidentiality respected, unless there are very convincing reasons to the contrary, for example, if abuse is suspected. However, every reasonable effort must be made to persuade the child to involve their parents or guardians and explore the reasons if the patient is unwilling to do so, particularly for important or life-changing decisions.

## **Is it legal to provide contraception, sexual and reproductive healthcare without parental involvement?**

Many of these principles are supported by statute. For example, the Sexual Offences Act 2003 provides a legal framework aimed at protecting children from sexual abuse. Under the Act, young people under the age of 16 still have the right to confidential advice on contraception, sexual and reproductive health. Most of the Act applies to England and Wales, with a small number of provisions applicable in Scotland and Northern Ireland. Furthermore, the Sexual Offences (Northern Ireland) Order 2008 lowered the age of consent to sexual activity in Northern Ireland from 17 to 16. In addition, it established that the provision of sexual health services to individuals under the age of 16 will not constitute an offence.

## **What if a doctor disapproves of young people being sexually active?**

Doctors 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: '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' (GMC – 0-18 years, paragraph 65).

## **What if a GP does not provide contraceptive services?**

GPs who do not provide contraceptive services must advise young people seeking those services of colleagues whom they could consult. It is acceptable for another GP to offer contraceptive advice and treatment to a competent young person in such circumstances. It must, however, be explained to the patient that it is in their medical interests for their GP to be informed if contraception has been prescribed and of any medical condition discovered, which requires investigation or treatment. This is particularly important if the patient is at the same time under the active clinical care of their GP or that of another doctor.

# 13

## Can sterilisation be performed on children and young people?

Sterilisation is occasionally requested for young women with serious learning difficulties. Although rarer, it may also be suggested as an option for a young man with learning difficulties. Sterilisation for contraceptive purposes should not normally be proposed for young people under 18, given that there are other options available. In the exceptional circumstances in which there is agreement that sterilisation is the best option for a young person, doctors should seek legal advice to obtain a court declaration.

### Key resources

Department of Health – Best practice guidance for doctors and other health professionals on the provision of advice and treatment to young people under 16 on contraception, sexual and reproductive health.

Available at: [www.dh.gov.uk/assetRoot/04/08/69/14/04086914.pdf](http://www.dh.gov.uk/assetRoot/04/08/69/14/04086914.pdf)

GMC – 0-18 years: guidance for all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)



# 14

## Sexual activity – additional obligations in Northern Ireland

### What is different about the law in Northern Ireland?

Section 5 of the Criminal Law (Northern Ireland) Act 1967 places a duty, unique to Northern Ireland, on everyone to report to the police information they may have about the commission of a relevant offence (one with a maximum sentence of five years or more). There are a few exceptions to the law. For example, 'medical confidentiality' is not, in and of itself, understood to be an exception.

### If the legal age of consent is 16, does this mean I have to report all underage sexual activity even where the activity is entirely mutually agreed and non-exploitative?

No, you do not have to automatically report all underage sexual activity. The Sexual Offences (Northern Ireland) Order 2008 makes some exceptions to the duty to report. Doctors are not under a duty to report sexual activity involving a child aged 13 to 15 where the other party is under 18.

### Does it affect my ability to provide contraceptive or sexual health advice to under 16-year-olds?

No, doctors can provide treatment to an under-16-year-old, without automatically having to report the child's sexual activity to the police, where it is to:

- protect a child from sexually transmitted infection
- protect the physical safety of a child
- prevent a child from becoming pregnant
- promote the child's emotional wellbeing by giving advice.

### What is the additional obligation in Northern Ireland?

The legal duty to report still applies where one of the parties is under 13, or 18 and over. So, for example, there is a duty to report sexual activity between an 18-year-old and a 15-year-old.

Where doctors are unsure of their duties and obligations, they should seek advice.

# 15

## Child protection

Where doctors have concerns about a child or young person who may be at risk of abuse or neglect, these concerns must be acted upon following local and national guidelines (see key resources box at the end of this section). The best interests of the child or children involved must always guide decision-making.

The GMC's guidance 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.
- e. Decisions made about children and young people must be made in their best interests.
- 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' (GMC – Protecting children and young people: The responsibilities of all doctors paragraph 1).

# 15

## Key resources

GMC – Protecting children and young people: The responsibilities of all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)

GMC – 0-18 years: guidance for all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)

Department for Education – *Working together to safeguard children Statutory guidance on inter-agency working to safeguard and promote the welfare of children*. Available at:

<https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>

Department for Education – Child sexual exploitation Definition and a guide for practitioners, local leaders and decision makers working to protect children from child sexual exploitation. Available at:

[www.gov.uk](http://www.gov.uk)

Department for Education – What to do if you're worried a child is being abused: advice for practitioners. Available at: [www.gov.uk](http://www.gov.uk)

Royal College of Paediatrics and Child Health – Child safeguarding toolkit. Available at: [www.rcgp.org.uk](http://www.rcgp.org.uk)

Royal College of Paediatrics and Child Health intercollegiate document – Safeguarding Children and Young People: Roles and Competences for Health Care Staff. Available at: [www.rcpch.ac.uk](http://www.rcpch.ac.uk)

National Institute for Health and Clinical Excellence – Child maltreatment: when to suspect maltreatment in under 18s. NICE clinical guideline 89. Available at: [www.nice.org.uk](http://www.nice.org.uk)

# 16

## 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 child protection 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) and in Scotland under the Prohibition of Female Genital Mutilation Act 2005 (as amended by the Serious Crime Act 2015). If a child, or young person is identified as being at risk of FGM, urgent safeguarding action must be taken. 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 to notify the police of FGM in England and Wales, if a young woman or girl aged under 18:

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

#### Key resources

##### UK-wide:

Royal College of Obstetricians and Gynaecologists – Female Genital Mutilation and its Management (Green-top Guideline No. 53) Available at: [www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg53](http://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg53)

Royal College of General Practitioners – resources available at: [www.rcgp.org.uk/policy/rcgp-policy-areas/female-genital-mutilation.aspx](http://www.rcgp.org.uk/policy/rcgp-policy-areas/female-genital-mutilation.aspx)

Royal College of Paediatrics and Child Health – resources available at: [www.rcpch.ac.uk/resources/female-genital-mutilation-resources](http://www.rcpch.ac.uk/resources/female-genital-mutilation-resources)

GMC – Protecting children and young people: The responsibilities of all doctors. Available at: [www.gmc-uk.org](http://www.gmc-uk.org)

Health Education England's FGM e-learning programme (available in all four nations, including for medical students). Available at: [www.e-lfh.org.uk](http://www.e-lfh.org.uk)

##### England and Wales:

HM Government – Multi-agency statutory guidance on female genital mutilation. Available at: [www.gov.uk/government/publications/multi-agency-statutory-guidance-on-female-genital-mutilation](http://www.gov.uk/government/publications/multi-agency-statutory-guidance-on-female-genital-mutilation)

##### Northern Ireland:

Department of Health-Multi-agency practice guidelines: female genital mutilation. Available at: [www.health-ni.gov.uk/publications/multi-agency-practice-guidelines-female-genital-mutilation-0](http://www.health-ni.gov.uk/publications/multi-agency-practice-guidelines-female-genital-mutilation-0)

##### Scotland:

Resources available at: [www.gov.scot/policies/violence-against-women-and-girls/female-genital-mutilation-fgm/](http://www.gov.scot/policies/violence-against-women-and-girls/female-genital-mutilation-fgm/)

# 17

## Compulsory treatment for a mental health condition

Due to the COVID-19 pandemic, temporary amendments to mental health legislation were introduced. Doctors are advised to access the most up-to-date guidance on mental health legislation and its application in clinical practice.

Doctors who are unfamiliar with the legislation and any temporary amendments should seek expert advice.

### When should mental health legislation be used?

In most cases, treatment and support for a young person'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 patients' severe mental illness is associated with a corollary lack of capacity, a mental health condition does not automatically diminish a patient's legal capacity.

Doctors who believe that the legislation may apply to one of their young 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) applies to all children and young people under 18. The Act contains some provisions and specific safeguards for under-18s. Amongst other things:

- 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 (SOAD) even if the child/young person consents to it unless it is an emergency
- children/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 recent independent review of the Mental Health Act. Details of any changes will be posted on the BMA website at: [www.bma.org.uk](http://www.bma.org.uk)

# 17

## What legislation is applicable in Scotland?

Where a patient is detained, the Mental Health (Care and Treatment) (Scotland) Act 2003 procedures must be followed. The Act contains some provisions and specific safeguards for under-18s. Namely, none of the regulated treatments for a mental health condition may be provided to an incapacitated patient who is 16 or 17 unless either the doctor in charge of care has a qualification, or special experience, in child and adolescent psychiatry or that doctor has sought and obtained an opinion in writing from a doctor who does. In addition, the practitioner appointed by the Mental Welfare Commission must have a qualification, or special experience, in child and adolescent psychiatry or another specialism appropriate for the treatment of the patient.

## What legislation is applicable in Northern Ireland?

The Mental Health (Northern Ireland) Order 1986 applies to all children and young people under 18. There are no specific safeguards for under-18s. New legislation combining both mental health and mental capacity law in Northern Ireland has been passed but has not yet been implemented. Details of any changes will be posted on the BMA website at [www.bma.org.uk](http://www.bma.org.uk)

### Key resources

#### England and Wales:

Department of Health – Code of Practice Mental Health Act 1983 (2015) – primarily chapter 19. Available at: [www.gov.uk/government/publications/code-of-practice-mental-health-act-1983](http://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983)

#### Scotland:

Mental Health (care and treatment) (Scotland) Act 2003: Code of Practice Volume 1 (2005). Available at: [www.gov.scot/publications/mental-health-care-treatment-scotland-act-2003-code-practice-volume-1/](http://www.gov.scot/publications/mental-health-care-treatment-scotland-act-2003-code-practice-volume-1/)

# 18

## Research and innovative treatment

### Can children and young people be involved in research and innovative treatment?

Children and babies should be eligible for inclusion in research and innovative therapy, with appropriate safeguards. To fail to do research would lead to stagnation of current practice and the continuation of medical management by using untried or unproven remedies, based on belief, rather than best evidence. The need for pharmaceutical products specifically designed for use by children has long been recognised. These need to be developed with the involvement of children and young people, once initial studies involving adults have proved the safety and efficacy of the product. There must be no financial reward to the child or parent (expenses are permitted) and all projects must be carefully scrutinised by a Research Ethics Committee (REC).

### Who can consent to their involvement in research and innovative treatment?

Families need support and independent advice about their options. The final decision about participation rests with patients (when competent) and with parents. Children and their parents must be given clear and appropriate information, with candid explanations of the purposes, risks and expected benefits of the research. If competent, the child must give unpressured and informed consent. Depending on the nature of the research, and the REC's view, parental consent may also be required, even if the child is competent.

### What if the parents consent but the child refuses?

When the procedures are more intrusive than those required for ordinary clinical care, a child's (verbal or non-verbal) refusal is a good reason not to proceed, even if parental consent has been obtained, unless it is in a child's best interests.

### What if one parent consents but another refuses?

Legally, the consent of one person with parental responsibility should suffice if the intervention is not contrary to the child's interests, and there are obvious circumstances when the consent of one parent has to be sufficient, eg because the child is in contact with only one parent. Nevertheless, the reasons for one parent refusing needs to be taken very seriously.

### Can children and young people be involved in emergency care trials?

Yes, children can take part in emergency care trials when there would be no time to seek initial consent before administering the medicine, if certain criteria are met. In 2008, the Medicines for Human Use (Clinical Trials) and Blood Safety and Quality Amendment was passed. As well as amending the Blood Safety and Quality Regulations 2005, this amended the regulations to enable children to be involved in emergency trials in certain circumstances.

#### Key resources

Medical Research Council – Medical research involving children.

Available at: [www.mrc.ac.uk](http://www.mrc.ac.uk)

Nuffield Council on Bioethics – Children and clinical research: ethical issues. Available at: [www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)

Guidance on clinical research involving infants, children and young people: an update for researchers and research ethics committees.

Available at: <https://adc.bmj.com/content/99/10/887>

# 19

## Useful contacts and addresses

British Medical Association, Medical Ethics and Human Rights Department, BMA House, Tavistock Square, London WC1H 9JP. Tel: 0300 123 1233. Web: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

General Medical Council, Regents Place, 350 Euston Road, London, NW1 3JN. Tel: 020 7189 5404. Web: [www.gmc-uk.org](http://www.gmc-uk.org)

Office of the Public Guardian and the Court of Protection (England and Wales), Archway Tower, 2 Junction Road, London N19 5SZ. Tel: 0845 330 2900. Web: [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

Office of the Public Guardian (Scotland), Hadrian House, Callendar Business Park, Callender Road, Falkirk FK1 1XR. Tel: 01324 678300. Web: [www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

Royal College of General Practitioners, 14 Princes Gate, Hyde Park, London SW7 1PU. Tel: 020 7581 3232. Web: [www.rcgp.org.uk](http://www.rcgp.org.uk)

Royal College of Paediatrics and Child Health, 50 Hallam Street, London W1N 6DE. Tel: 020 7307 5600. Web: [www.rcpch.ac.uk](http://www.rcpch.ac.uk)



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BMA 20210382