Consent and children

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Abstract

The law relating to consent for medical interventions in children is complex. Children, when they are old or mature enough, can consent for themselves. When they are unable to do so, consent must be sought from someone with parental responsibility. This article discusses consent, and its refusal, to medical interventions by children and adolescents.

Keywords Best interests; capacity; child; consent; parental responsibility; research ethics

Royal College of Anaesthetists CPD Matrix: 1F01, 1F05, 3D00

Learning objectives

After reading this article, you should be able to:

- list the elements of capacity to consent
- discuss when children can consent to medical interventions
- identify who has parental responsibility, and can consent on behalf of a child who lacks the capacity to consent
- outline how to proceed when there is a disagreement around consent to a medical intervention

What is a child?

According to the United Nations Convention on the Rights of the Child (UNCRC),[1] every person under the age of 18 years is considered a child. This position is reflected in legislation in the various jurisdictions of the UK and Ireland. Also identified by the Convention and domestic legislation is the idea that children are individuals with rights that should be respected. This entails seeking their views on matters that affect them, listening to them, and taking into account what they have to say. In general, this would mean respecting their decisions, and their rights to confidentiality. However, children are not a homogenous group. From an anatomical, physiological and psychological perspective there are very obvious differences between a 16-year-old adolescent and the 3-month-old baby. The latter clearly lacks the ability to participate in healthcare decision making, whereas the average adolescent can, and should, be fully involved. Both of these individuals deserve protection, but for the adolescent identifying the correct balance between protection and respecting their views can sometimes be hard. And thus the law relating to medical consent and children is necessarily complex, and sometimes restricts the decisions children are allowed to make. The right to full decision making only starts once the threshold age of 18 years is reached. However, in all jurisdictions of the UK and Ireland, a child (who has capacity) can legally consent to most medical procedures once they are 16 years old. Because of these gradations, many guidance documents (such as the GMC's *0–18 Years*) refer to persons under 16 years as children, and to those aged 16 and 17 years as 'young people'.[2]

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Best interests

It is expected that doctors will always act in the best interests of children and young people. While this is a sound guiding principle, it is not always straightforward to calculate what the child's best interests are, and sometimes there may be competing ethical demands. For example, they (or their parents) might request a procedure that is not medically best for them, or refuse one that is; or the child might reveal some information to a doctor which they wish to be kept confidential, but doing so might place the child at risk of harm or breach legal reporting requirements. In some circumstances it can be difficult to find a balance between protection and respect for the child's opinion. It is important to understand that 'best interests', even in the context of healthcare, do not solely refer to medical best interests, but should also take into account familial, social, cultural and other relevant factors. Sometimes, even after considering all of the ethical and legal aspects of a situation, it can still be challenging to reach a satisfactory answer to a 'best interests' question. Where a doctor has concerns about whether a particular decision is ethical, lawful or even good for the child, then they should seek advice from senior colleagues, designated child protection doctors, the relevant regulatory authority, or the hospital's legal representatives.

Consent

Consent to a medical intervention or treatment is an ethical, professional and legal requirement of anaesthetic practice. Except in an emergency, it is unlawful to treat a child without consent – this can be provided by either the child/young person themselves if they are mature or old enough, or from their parent/legal guardian, if not. For consent to be considered valid, three criteria must be fulfilled: it must be (i) informed, and (ii) provided voluntarily by (iii) a person with the capacity to do so. As an essential element, doctors are expected to provide all relevant information in a comprehensible, comprehensive and timely manner.[3]

- Patients must understand to what they are giving consent. This means that children (and their parents/legal guardians) should be given information about the anaesthetic aspects of the child's care in language that is age appropriate, and using tools that assist the child in understanding. Even where children will not be consenting for themselves (for reasons of age or immaturity) they should be included in the conversation. Anaesthetists therefore need to discuss any proposed procedures and include the

reasons for these, any material risks (see below), and any possible alternatives. This latter issue may be particularly important with respect to perioperative regional anaesthetic techniques where, in paediatrics, there may be potential risks but no established benefits over other pain management possibilities.

- The information should be provided sufficiently in advance of the procedure, to allow the child/parent/guardian to consider it and ask any questions. Because of the number of children who are admitted on the day of surgery there is a practical difficulty in having such discussions within an appropriate timeframe. Therefore, relevant information should be provided in advance in writing, and in a manner that takes account of variable levels of health literacy, and the primary language of the patient (see for example https://www.rcoa.ac.uk). For children, this information might be most accessible to them if provided via the internet, or on social media platforms. There should be an opportunity for children and their parents/guardians to ask questions, and these should be answered openly and honestly. Deception (regarding the proposed procedures) by parents, or anyone involved in the care of the child, should not be practised or endorsed by the anaesthetist or other treating physician. Parents or children do sometimes seek specific information about the surgical procedure. In general, it is for the relevant surgeon to answer these questions.
- The Association of Anaesthetists of Great Britain and Ireland (AAGBI) have recently produced new guidelines on consent for anaesthesia (2017).[4] The AAGBI base their discussion on 'how much information is required' around the UK Supreme Court decision in *Montgomery v Lanarkshire Health Board (2015)*.[5] With regard to what risks should be discussed — the AAGBI guidelines state that a doctor needs to provide information on 'all material risks'. These are risks to which 'a reasonable person in the patient's position would be likely to attach significance', or to which 'the doctor should reasonably be aware that the particular patient would be likely to attach significance to it'. This is broadly similar to the position of the Irish courts, and to the guidance offered by the GMC and the Irish Medical Council. While *Montgomery v Lanarkshire Health Board (2015)* was a case about adults, the same level of information should be provided to young persons who are consenting for themselves, or to their parents/legal guardians who are providing consent on their behalf.
- It is emphasized in all guidance that consent is a process — an ongoing dialogue between the doctor and the child and their parents/guardians. The discussion should be tailored to meet their uncertainties, needs and wishes.

Who can provide consent

- Consent to medical treatment of a child or young person can be provided
  - by the child or young person if they are competent (see below), or
  - by their parent/legal guardian if they are not; or
  - by the court if neither of these is possible.
- Emergency treatment can be provided without consent if it is necessary to save the life, or prevent serious harm to the health, of a child or young person.
- The legal right to consent to medical treatment is both age and jurisdiction dependent.

Persons older than 18 years

All individuals with capacity have the right to consent to, and refuse, all treatments, regardless of whether their choice might seem unwise or ill-thought out. Capacity refers to the ability of a person to understand the nature, purpose and potential consequences of undergoing (or not) a medical intervention. In order to make a decision in respect of treatment or investigtion, they must receive all of the relevant information in a comprehensible manner, retain it for long enough to consider and weigh it, and they must then communicate that decision.

Persons 16–17 years

In all jurisdictions in the UK and Ireland there is a presumption that young people over the age of 16 years have the capacity to consent to most forms of medical intervention. There are a few exceptions - they cannot, for example, consent to act as a living solid organ donor in England, Wales and Northern Ireland (*Human Tissue Act, 2004*),[6] nor can they complete an Advance Healthcare Directive.

If there is concern about the decision-making capacity of a young person, it is up to the doctor to rebut the presumption of capacity — i.e. to clearly demonstrate where in the process of retention, understanding, considering, reaching a decision and communicating it, that the patient fails. Even having done all of this, the doctor should be sure that they have provided the relevant information in an understandable way, and consider whether reiterating it in a different manner might assist the patient. A child who has learning difficulties should not be considered to automatically lack capacity - they possess the same legal rights to self-determination as other children do.

When a 16 or 17 year-old child lacks the capacity to consent, the legal framework (in respect of non-emergency interventions) varies across jurisdictions.

- In England, Wales, Northern Ireland and the Republic of Ireland (ROI), those with parental responsibility (see below) can consent to medical interventions that are in the best interests of the young person.
- In England and Wales, such interventions can be carried out in the in the best interests of the young person, without parental consent. However, the views of those with parental responsibility are likely to be important when evaluating the best interests of the young person, not least in that they may assist in determining the past and present wishes, and feelings, of the young person.
- In Northern Ireland, treatment for a non-competent child can be provided without parental consent if a parent cannot be contacted and there is a need to proceed.
- In Scotland, those over 16 who lack the capacity to consent are subject to the same legal safeguards as adults who lack capacity.

Persons younger than 16 years

- Despite being younger than the statutory age of consent, some children are recognized as being of 'sufficient

understanding and intelligence to enable him or her to understand fully what is proposed' — they are mature enough to make their own medical decisions. This is frequently referred to as *Gillick competence*.[7] In general, such children should be encouraged to involve their parent(s) in the decision-making process but in exceptional circumstances, where the child cannot be so persuaded and their health will be impacted by non-treatment, or it is in their best interests to provide treatment without parental knowledge, then it is reasonable to proceed. While *Gillick competence* per se has not yet been recognized by courts in the ROI, the principle of treating children (deemed to have capacity) younger than 16 years without parental knowledge *in exceptional circumstances* has been acknowledged by the Health Service Executive in their *National Consent Policy*.[8]

- It is important to make individualized assessments of maturity and understanding in light of the nature of the decision to be made. For example, a young person may be able to consent to a relatively simple, low-risk procedure, but might not have the capacity to consent to one that is difficult, complex or risky.
- Where the child lacks capacity, consent can be provided by a person with parental responsibility. In the vast majority of cases, but not always, this will be the biological parent(s). Parental responsibility relates to the rights and responsibilities that parents have in law for their child. This includes the right to consent to medical treatment for them, up to the age of 18 years in England, Wales, Northern Ireland and ROI, and 16 years in Scotland. The child's mother is almost always a person with parental responsibility (unless this has been restricted by a court order). This is still the case if the child is in voluntary care.
- However, the biological father is not automatically a person with parental responsibility. He is, if he:
  - is, or was, married to the mother at the birth of the child (divorce or separation does not affect this); or
  - in Scotland, if he has been married to the mother at any point since conception; or
  - if unmarried, has a parental responsibility agreement with her; or
  - has been granted parental responsibility through the courts (married step-parents and registered civil partners can acquire parental responsibility in this way); or
  - has his name on the birth certificate (for children born after 15th April 2002 [Northern Ireland]; December 1st 2003 [England and Wales]; May 4th 2006 [Scotland]); or
  - in ROI, if he has cohabited continuously with the mother for 12 months, at least 3 of which have been since the birth of the child.
- Other parties who may provide consent in certain circumstances include
  - adoptive parents (including prospective adoptive parents once the child has been placed with them)
  - a legally appointed guardian
  - a representative of the local authority with
    a. an Emergency Protection Order; or
    b. a Residence Order; or
    c. a Care Order for the child.

Refusal of consent

Situations can and do arise where there is refusal to consent to a medical procedure. To proceed without consent (except in an emergency) is to commit the tort of battery, or the crime of assault. Refusal can come from the child, or their parents, or both. Open discourse and good communication are key to resolving such issues. Most cases can be successfully negotiated with ongoing discussion, the provision of a second opinion, or in-hospital mediation. Where refusal remains resolute, then consideration must be given as to whether the medical intervention is still in the child's best interests, all things considered. Legal advice, and an application to the courts may be required to resolve this issue. There are, however, some differences between jurisdictions.

Persons older than 18 years

As stated previously, adults with capacity have the right to refuse all or any medical interventions.

Persons 16 and 17 years

- If a young person consents to treatment that is clinically appropriate, then a parental refusal cannot override this.
- If a young person refuses treatment that is life saving, or would substantially improve (or prevent serious deterioration to) their health, this presents a difficult and complex challenge.
  - In Scotland, a young person with capacity has the same rights to refuse as an adult.
  - In England, Wales and Northern Ireland, the situation is less certain. To date, the courts have generally considered that providing treatment in serious or lifesaving situations is in a young person's best interests. However, doctors seeking to provide medical interventions against the wishes of a young person should seek legal advice prior to acting.
  - In ROI, a recent case considered the right of a 17-year-old male to reject chemotherapy contrary to both the wishes of his mother and medical advice. The court decided that the young person in question could not be forced to undergo treatment that he did not want. However, this case should not be taken to indicate that a similar respect will be accorded to the opinion of a different refusing young person in the future. Again, doctors wishing to provide medical interventions in a situation where a young person refuses to consent should seek legal advice.

Persons younger than 16 years

- In cases where children considered *Gillick competent* refuse to consent to a procedure that is in their best interests it would be prudent to seek legal advice.
- Where a child is not *Gillick competent*, parental consent can be relied upon to proceed. However, if a child refuses to co-operate, despite parental consent, consideration needs to be given as to how the procedure will happen, and if the child resists, how this will be overcome without acting in a manner that is contrary to the child's best interests.

- Occasionally, parents disagree with each other. There may be a difference of opinion between the parents of the child about whether a particular medically proposed procedure is in their child's best interests or not. If disagreement persists, despite appropriate attempts at mediation, it will be necessary to seek the guidance of the court.
- On rare occasions doctors may be asked to provide treatment that they do not believe is in the best interests of the child. While there is no obligation on a doctor to provide such treatment, should the parental request persist it would be prudent to seek advice from senior colleagues, and/or get a second opinion. Should these measures fail to resolve the issue, legal advice should be sought.

Research

Involving children (or their data) in research and clinical trials is subject to the same ethical and consent principles that apply to adult research, with some additional considerations:

- It is important to involve the child in discussions about their inclusion in research, and age appropriate information should be provided.
- As with other medical interventions, formal consent should be obtained and documented prior to enrolment. Where a study will run over a long period, consent should be periodically reaffirmed, as the child's capacity, or legal status, may change.
- Where a child lacks capacity, a person with parental responsibility may provide consent to their participation in research. However, the Royal College of Paediatrics and Child Health (RCPCH)[9] recommend that the child's active agreement (assent) should be sought. The RCPCH indicate that children should be capable of providing this by the age of 7 years.
- Where a child refuses to (or withdraws) assent or consent, this dissent generally should be respected, even if a parent provides consent and wishes their child's participation to continue. The child's dissent is legally determinative in the case of Clinical Trials of Investigational Medicinal Products.[10] ◆

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