

Ethical issues in  
paediatric organ  
donation —  
a position paper  
by the UK  
Donation Ethics  
Committee  
(UKDEC)

June 2015

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# Executive Summary

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1 At present there is no clear ethical framework for donation from children and it appears that there is a wide range of views about what constitutes best practice in this area. For an adult donor, decisions about organ donation are generally made on behalf of a person who lacks capacity on the basis of that person's known wishes and beliefs. However the way in which decisions about organ donation are made on behalf of children differs because of the following significant factors:

- Children have differing abilities to make decisions depending on their age or maturity and many children are unable to make any decisions at all
- Very often there is little or no evidence of a child's wishes or beliefs on which to base a decision about donation
- The model of care in paediatric medicine is more family-centred than in adult medicine. This means that, working within the bounds of the child's interests, paediatricians encourage families to reach a decision about a child's care that is right for the family as a whole and which therefore takes into account the interests of a wider group of people than just the child who is the patient.

2 In this paper, UKDEC examines the particular ethical issues which arise in gaining consent for organ donation from children, and how practices in end of life care for children affect decision-making about organ donation. UKDEC proposes a model of decision-making which respects any known wishes or beliefs of the child but which, in the absence of these, provides a framework for making decisions about organ donation. UKDEC concludes that a decision to donate a child's organs can enable actions to be taken to facilitate donation where such actions are not against a child's interests.

3 A number of specific areas of ethical concern in paediatric organ donation are also examined. At present organ donation from neonates does not occur in the UK and we discuss the particular concerns that arise in relation to donation from this group. We also examine organ donation from children whose death would be referred to coroners and suggest that in some cases more could be done to facilitate donation from this group. Finally we discuss the benefits of donating a child's organs for research where donation for therapeutic purposes is not possible.

# Summary of recommendations

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## **Recommendation 1**

Provided decisions are not against their child's interests, parents' values and beliefs should be allowed to determine whether they wish their child to be an organ donor, and if so whether to consent to interventions aimed at increasing the chances of a successful donation.

## **Recommendation 2**

Where a family is willing to consent to the removal of organs that are viable for transplantation, then the hospital has a responsibility to make this happen if it is possible.

## **Recommendation 3**

A decision made by a child with capacity that they would not want to donate organs after their death should always be respected.

## **Recommendation 4**

Where a child has indicated willingness to donate (for example by registering on the ODR), has not expressed a view either way or lacks the capacity to make such a decision, then clinicians should work with the child's family to reach a decision that takes account of any information about the child's views but also works for the family as a whole.

## **Recommendation 5**

It would be ethically acceptable for organ donation from anencephalic infants to proceed with the consent of the parents after death has been confirmed by circulatory criteria.

## **Recommendation 6**

Consistent with our earlier recommendation, the parents' values and beliefs should be allowed to determine whether their anencephalic child is intubated and ventilated, provided this is not against their child's interests. Precautionary sedation and analgesia would be needed to ensure this condition is met.

## **Recommendation 7**

Health Departments and those responsible for coronial services in England, Wales and Northern Ireland might consider how the formal agreement on organ and tissue donation between the Procurator Fiscal Service and the Scottish Transplant Group could be adapted to work in the rest of the UK.

## **Recommendation 8**

Consideration should be given to reviewing the Royal College of Pathologists and Royal College of Paediatrics and Child Health protocol for post mortems to identify the cause of sudden unexpected death in infancy in the context of organ donation.

## **Recommendation 9**

When parents would like to donate their child's organs for transplantation but this is not clinically possible, clinicians should attempt wherever possible to accept such organs for research, if this is an acceptable alternative to the parents.

# Terminology

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In this guidance, the term “donor” is used to mean the person from whom organs or tissue have been removed. This is in line with the Human Tissue Act 2004, s.7 which uses this definition of a donor. The Act also states in s.8(6) that material is the subject of donation if appropriate authority exists in relation to it, and it is in this sense that the term “donation” is used here.

## The role of UKDEC

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- 2 UKDEC was established in January 2010, following a recommendation by the Organ Donation Task Force (ODTF) that:

‘urgent attention is required to resolve the outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Committee should be established.’

- 3 UKDEC’s role is to consider ethical issues relating to the field of organ donation and transplantation and provide independent advice to clinicians, policy leads and others.
- 4 There are two guiding principles underpinning ethical frameworks and guidance developed by UKDEC. These are:

### Principle 1

Where donation is likely to be a possibility, full consideration should be given to the matter when caring for a dying patient; and

### Principle 2

If it has been established that further life-sustaining treatment is not of overall benefit to the patient, and it has been further established that donation would be consistent with the patient’s wishes, values and beliefs, consideration of donation should become an integral part of that patient’s care around the time of death (both pre- and post-mortem).

## Clinical context

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### Caring for children at the end of life

- 5 Death in childhood is relatively uncommon. However, when a very ill child cannot benefit directly from further treatment and will inevitably die, attention will shift to providing the best possible end of life care for that child first and foremost, but also to providing a good end of life experience for the family as a whole. End of life care for children often involves, for example, encouraging parents to hold their dying child after treatment has been withdrawn and inviting parents to spend time with their child after death.
- 6 Wherever possible, children will be involved in decision-making about their care. However, this will not always be feasible and parents will need to make decisions on their children's behalf. Whilst the child's interests and views (if available) will be respected and protected, the health care team will also be committed to caring for the family as a whole. That is why the model of care in paediatric medicine is often described as one of family-centred care. For this reason it can be difficult to translate principles fashioned in an adult environment into one for children.

### Donation & Transplantation

- 7 The number of children who can become organ donors is limited by several factors. As stated earlier, death in childhood is relatively uncommon, and many children who die will have received aggressive medical therapies, or suffer from diseases that preclude successful transplantation of their organs. In addition, organ donation is only possible when a child dies in hospital, so many children, for example those who die at home, will not be able to become donors.
- 8 In 2013/14 in the UK, organs were donated by 55 children who died in critical care units. Just over two thirds of these donations (38) took place after confirmation of brainstem death (DBD). The remaining 17 donations took place after confirmation of circulatory death (DCD).<sup>1</sup>
- 9 Organ failure is relatively rare in childhood and most childhood deaths from organ failure occur in those for whom a transplant would have offered no benefit. As a result there are relatively few children awaiting transplantation and so a significant proportion of the organs from paediatric donors will be transplanted into adults. It is important therefore that families considering organ donation understand that the organs donated by their child may not go to another child.

### Including donation in end of life care

- 10 Just as it is important that children should be involved wherever possible in making decisions about their care, decisions about organ donation, too, should take account of any evidence of a child's wishes or beliefs.
- 11 It is crucially important to acknowledge that parents of potential donors are firstly grieving parents, and donation should only be pursued as part of a well planned and sensitive programme of care that protects their interests in addition to those of their child.
- 12 If families agree to donation, clinicians should ensure that the child's end of life care is as consistent with usual practice in paediatric medicine as is possible and that families are given the same choices as they would have been had they not considered donation. In some cases this may mean that families will make choices that are incompatible with donation (such as taking the child home to die or holding their child after death) and it is important that their freedom to do so should not be undermined. If such practices rule out the possibility of donation, families should be made aware of this.

- 13 The potential to help others will be seen as a welcome opportunity by some families. Involving families<sup>2</sup> in decision-making about their child's care, including decisions about donation, is a powerful way of helping them feel in control – this can have a significant effect on how the experience is remembered.
- 14 For some parents the choice to donate their child's organs can result in positive memories of what their child achieved, even in death<sup>3</sup>. It is therefore important that parents' choices should not be unnecessarily restricted where donation is a possibility, as the chance of creating a lasting legacy through organ donation could be very important to the family.



## The need for an ethical framework for paediatric donation

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- 15 The Organ Donation Taskforce (ODTF) suggested means by which the adult donor pool might be increased, recommending that outstanding ethical and legal issues be resolved, but made no specific recommendations about children.<sup>4</sup>
- 16 UKDEC held a workshop on 7th October 2011 at which a presentation was given on paediatric heart transplantation. The resulting discussion suggested that there may be particular difficulties in relation to donation of organs from children that went beyond the specific issue of the donation of hearts. These centred on the assumptions about what can reasonably be expected to be in the interests of a potential child donor in the hours leading up to their death, and those after death and prior to the removal of organs/tissue.
- 17 UKDEC has echoed the advice from the Department of Health (England and Wales),<sup>5</sup> the Scottish Government Health Directorates<sup>6</sup> and the Department of Health, Social Services and Public Safety (Northern Ireland)<sup>7</sup> that successful transplantation is in the interests of a willing donor. This suggests that measures that are necessary to secure donation and then successful transplantation are, within limits, in the interests of those patients where consent for donation has been given by them or on the basis of their wishes. It is not immediately obvious that this assumption holds for all children, especially young children<sup>8</sup>. This is because children, especially those who are very young or immature, may not have formed any views or held any beliefs or values that can be used to inform decisions about their wishes in relation to organ donation.
- 18 There is no clear ethical framework for donation from children and representations to UKDEC suggested that practitioners have a range of views and concerns about what constitutes best practice in paediatric donation.
- 19 Accordingly, this paper explores the ethical and legal issues in relation to donation from children. These include considerations regarding consent and also the special circumstances that surround the care of children.

## Legal context

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- 20 This paper describes UKDEC's understanding of the legislation governing decisions about organ donation. However any clinician with practical concerns about the impact of the various pieces of legislation on their decision-making should seek their own independent legal advice.

### Before death

- 21 Prior to death, decisions regarding end of life care for the child patient must be made either by the child, if they have capacity, or by someone with parental responsibility<sup>9</sup>. In practice most decision-making will be collaborative with the health care team supporting the child and their parents. The usual standard for decision-making is the child's best interests. In making a decision in the child's best interests, the child's welfare must be paramount<sup>10</sup>. It is accepted that: '[t]he term 'best interests' encompasses medical, emotional, and all other welfare issues.'<sup>11</sup> We will assume here that the child's parents have parental responsibility.
- 22 The capacity of children to consent to, or refuse consent for, treatment does not map neatly onto their chronological age. Nonetheless, there is an age above which it might be assumed that most children are likely to have at least some capacity and an age below which they are unlikely to have developed any capacity. For convenience, issues will be considered here in three broad age groups, whilst recognising that these do not provide hard and fast boundaries.
- A **Adolescents (e.g. approximately 12-17)**
- 23 In this category it is more likely that the child will have capacity to consent to treatment at the end of life. If the child lacks capacity, it is more likely that information will be available about their wishes, feelings, beliefs and values that can be used in assessing their best interests. If so, then their best interests can be determined in the same way as for adults<sup>12</sup> but parental consent must also be obtained.
- B **Children (e.g. approximately 8-11)**
- 24 In this category, although the child is unlikely to have capacity to consent to treatment at the end of life, it is possible that some information will be available about the child's wishes, feelings, beliefs and values that can be used in assessing the child's best interests.
- C **Infants and young children (e.g. approximately 0-8)**
- 25 In this category the child is unlikely to have capacity to consent to treatment at the end of life, and it is unlikely that there will be any information available about the child's wishes, feelings, beliefs and values that can be used in assessing the child's best interests.

### After death

- 26 In all UK jurisdictions, a decision made during life by an adult or child<sup>13</sup> with capacity to consent to or authorise organ donation after their death provides the legal authority to proceed with donation. Equally, a decision to refuse to donate made during life remains in force after the person's death (see the Appendix for more detail on the legal context for decisions about donation after death).

# An ethical framework for making decisions about donation

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27 UKDEC has argued in the case of adults that where a clinical team has reached the conclusion that continuing with life sustaining treatment is no longer in the patient's best interests, the possibility of organ donation should be available and offered to the patient and/or their family<sup>14</sup>. Accordingly, we are minded to assume that the same applies to children, so that, if the clinical team have reached the conclusion with the parents' agreement that continuing life-sustaining treatment is no longer in the best interests of a child patient who lacks capacity, the possibility of organ donation should be available and offered to that child's parents. Moving paediatric care in this direction would be consistent with the Organ Donation Taskforce's goal of making the offer of donation 'usual and not unusual'<sup>15</sup>. Building on the NICE guidance on organ donation<sup>16</sup>, the UK Paediatric Intensive Care Society (UKPICS) recently made recommendations on approaching families in this context.<sup>17</sup>

## Decisions before death

28 As discussed in paragraph 17 above, making decisions about a child's best interests is challenging in this context because children, especially those who are very young or immature, may not have formed any views or held any beliefs or values that can be used to inform decisions by parents about organ donation.

29 For the best interests test to be relevant, two conditions must be met. First, there must be evidence available upon which to base a decision about where an individual's interests lie and how these interests are best served. In the context of organ donation, evidence about the child's wishes, feelings, beliefs and values would be necessary to achieve this. Often (most commonly for younger children) there is little or no such information available. Many children will not have previously reached a level of capacity to be able to express feelings, beliefs or values in relation to organ donation. Second, the child must have the potential to benefit from, or be harmed by, the outcome of the relevant decision. This may not be the case in the context of organ donation, where an earlier decision has already been made that the withdrawal of life-sustaining treatment is in the child's best interests, and so the potential for such benefit is limited.

30 When one or both of these conditions are not met, there are precedents for alternative approaches to healthcare decision-making in relation to children who lack capacity. In its guidance for doctors treating children and adolescents, the General Medical Council advocates a slightly different test in the context of paediatric research, assessing whether participation in a research project 'does not go against [the child's] best interests or involves only minimal or low risk of harm'<sup>18</sup>. The Royal College of Paediatrics and Child Health took a similar position in its guidelines on the ethical conduct of research involving children<sup>19</sup>. Both guidance documents rely on a decision of the House of Lords which used a test of 'not against the [child's] interests' on the grounds of the public interest in determining paternity by blood testing and the minimal risk of harm involved.<sup>20</sup>

31 In the context of end-of-life care, it is accepted that parents sometimes make decisions about the timing of the withdrawal of life-sustaining treatment in the interests of others (usually other family members). This is another example of a decision that does not benefit the child directly, but is of wider benefit and is *not against* the child's interests.

32 This broader approach fits well with organ donation and UKDEC recommends a similar approach to decisions about organ donation, including pre-mortem interventions, relating to infants and young children.

# An ethical framework for making decisions about donation

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## Recommendation 1

Provided decisions are not against their child's interests, parents' values and beliefs should be allowed to determine whether they wish their child to be an organ donor, and if so whether to consent to interventions aimed at increasing the chances of a successful donation.

### **Making decisions about donation after death**

- 33 Where the potential donor has provided legally effective consent (for example by registering on the Organ Donor Register (ODR)), the norm is still to seek the agreement of relatives before continuing to donation even though this is not legally necessary. This practice appears to give the final say to relatives rather than the donor, potentially enabling relatives to undermine the donor's wishes. In paediatric care where decision-making is more customarily family-centred, clinicians will be used to working towards a position where a decision works well both for the child and the wider family. This would be the goal in any case where donation became an option.

## Recommendation 2

Where a family is willing to consent to the removal of organs that are viable for transplantation, then the hospital has a responsibility to make this happen if it is possible.

## Recommendation 3

A decision made by a child with capacity that they would not want to donate organs after their death should always be respected.

## Recommendation 4

Where a child has indicated willingness to donate (for example by registering on the ODR), has not expressed a view either way or lacks the capacity to make such a decision, then clinicians should work with the child's family to reach a decision that takes account of any information about the child's views but also works for the family as a whole.

### Donation from neonates

- 34 At present, professional standards – especially governing the confirmation of death in young children – restrict the overall number of small donors in the UK. In relation to neonates, organ donation is extremely rare.
- 35 The death of a newborn child is a tragic event for any family, and supporting the bereaved family should be paramount at such a time. Nevertheless, there may be some parents who would value the opportunity to donate organs.
- 36 In relation to donation after brainstem death (DBD), the Academy of Medical Royal Colleges recommends that neurological criteria are not used to diagnose death in neonates who are less than two months of age<sup>21</sup>. This position is in contrast to North American, European and Australasian practice<sup>22</sup>. UKDEC supports the decision of the Royal College of Paediatrics and Child Health to revisit the issue of diagnosing death in infants less than two months of age.
- 37 Offering families the possibility of donation after circulatory death (DCD) has not yet become part of end of life care for neonates in the UK, although for adults and older children it has grown rapidly in recent years and now accounts for over 40% of deceased donors.<sup>23</sup>
- 38 For families who would value the opportunity to donate, DCD could be considered for neonates with birth asphyxia for whom continued life-sustaining treatment is no longer in their best interests.

### **Donation from anencephalic infants**

- 39 DBD is not an appropriate donation pathway for anencephalic infants, as the brain stem is usually preserved and some degree of brain stem function will often be present. Additionally the absence of large parts of the brain means that the standard tests cannot meaningfully be interpreted for death to be safely confirmed using neurological criteria.
- 40 Donation from anencephalic infants is rare in other countries and UKDEC is not aware of any recent examples. The last documented case outside the UK is from 1999 in Italy<sup>24</sup>. UKDEC is aware of one case of donation from an anencephalic infant in the UK, and was approached by the clinical team for ethical advice in relation to another case where donation did not proceed for clinical reasons.
- 41 DCD could be considered in such cases but this would require either a surgical organ retrieval team in readiness at the birth or elective intubation of the infant at the time of birth to allow donation options to be explored over the coming hours. Interventions to facilitate DCD from anencephalic infants should be seen on a spectrum, with intubation and ventilation being one of the most invasive.

### **Recommendation 5**

It would be ethically acceptable for organ donation from anencephalic infants to proceed with the consent of the parents after death has been confirmed by circulatory criteria.

### **Recommendation 6**

Consistent with our earlier recommendation, the parents' values and beliefs should be allowed to determine whether their anencephalic child is intubated and ventilated, provided this is not against the child's interests. Precautionary sedation and analgesia would be needed to ensure this condition is met.

### **Cases involving the Coroner or Procurator Fiscal**

- 42 It is not unusual in North America for coroners to give permission for children dying as a result of head injuries to donate organs, even when these injuries have possibly been inflicted by a third party.
- 43 Any death that is referred to the coroner is more complex at some level. However, this need not exclude offering the possibility of organ or tissue donation as a normal part of end of life care. The non-accidental death of a child is particularly tragic, and there are additional sensitivities if a parent is suspected of involvement. Where such a death occurs everyone will be working to balance the interests of the child, the needs of the whole family, and the requirements of the legal processes. Whilst it might be particularly challenging to facilitate donation in such circumstances, it should remain a possibility for all families and it should be supported as fully as possible where either the child or the family have clearly stated their wish to donate.
- 44 Coroners must be able to carry out their statutory duties without compromise whenever the unexpected death of a child occurs. However, for most deaths that are referred to the coroner, organ donation should remain a possibility. Clinicians should not make assumptions about what a coroner might agree to, or be reluctant to approach a coroner regarding donation, as even where a child's death has occurred in suspicious circumstances some donation may be possible.
- 45 Coroners need enough information to make a balanced and considered decision in line with their statutory duties – the provision of timely and comprehensive information about the cause and circumstances of death is key to allowing coroners to make an assessment about the possibility of donation without undermining their ability to carry out their role effectively.
- 46 UKDEC notes that the Scottish Government and the Scottish Transplant Group has a formal agreement with the Crown Office and Procurator Fiscal Service about organ and tissue donation. They have a very good track record of building links such that Procurators Fiscal are now more willing to facilitate donation where possible.

## **Recommendation 7**

Health Departments and those responsible for coronial services in England, Wales and Northern Ireland might consider how the formal agreement on organ and tissue donation between the Procurator Fiscal Service and the Scottish Transplant Group could be adapted to work in the rest of the UK.

## Sudden unexpected death in infancy (SUDI)

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- 47 The Royal College of Pathologists and Royal College of Paediatrics and Child Health protocol for post mortem to identify the cause of SUDI requires forensic pathologists to carefully scrutinise all organs in detail. This scrutiny precludes consideration of organ donation, even if a parent were voluntarily to raise it as a possibility.<sup>25</sup>
- 48 The potential beneficial effects that organ donation may afford bereaved families are not, therefore, currently available in the case of SUDI.

### Recommendation 8

Consideration should be given to reviewing the Royal College of Pathologists and Royal College of Paediatrics and Child Health protocol for post mortems to identify the cause of sudden unexpected death in infancy in the context of organ donation.



## Donation for research

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- 49 Sometimes parents would like to donate their child's organs but this is not clinically possible, for example if the child died as a result of cancer.
- 50 In this situation it might be appropriate to discuss the possibility of donation for research purposes, which would hopefully contribute to saving lives or improving health in the future.
- 51 In response to our consultation, we heard evidence that the act of donation can have a positive effect on families' experience of bereavement, which may be undermined if an offer to donate is not taken up. For the family whose child cannot donate directly for transplantation purposes, research may provide a valuable alternative opportunity.
- 52 Families' expectations must, however, be carefully managed. Those agreeing to donation may assume that their child's organs will be used to benefit others immediately. Information on what the organs may be used for, and the likelihood of their being used, should be included in discussions about donation for research.

### Recommendation 9

When parents would like to donate their child's organs for transplantation but this is not clinically possible, clinicians should attempt wherever possible to accept such organs for research, if this is an acceptable alternative to the parents.

## Appendix: The legal context for decisions about donation

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### 1 Organ donation under the Human Tissue Act 2004 (HTAct)

In England, Wales and Northern Ireland, organ donation can only proceed if consent to that donation is available under the HTAct. Consent can be provided either by the donor<sup>26</sup> or by a third party.

In the case of a child, either:

- a. consent to donation after death is available from the donor child<sup>27</sup>
- b. consent to donation after the donor child's death will be provided by someone with parental responsibility for the child (usually a parent) or where no person had parental responsibility for the child immediately before he died, the consent of a person who stood in a 'qualifying relationship' to him at that time

2 Both categories will include a spectrum of possibilities. The first category will include: (i) donors who have both consented to donation and agreed to undergo some or all procedures which would increase the probability of a successful transplant; (ii) donors who have simply consented to donation by joining the Organ Donor Register or signing a donor card; and (iii) donors who have consented to donation without performing one of the formalities in (ii).

3 Within the second category (1b. above), although most consent providers will be influenced by the donor's wishes, there is no requirement in the HTAct for the consent to reflect the donor's wishes. Cases in this category could therefore encompass: (iv) donors who have consented to donation, but consent is nonetheless sought from someone with parental responsibility or a person in a qualifying relationship to the donor; (v) donors for whom consent is provided on the basis of their wishes and feelings; (vi) donors for whom consent is provided on the basis of the beliefs and values that would be likely to influence their decision; and (vii) donors for whom consent is provided even though there is little or no evidence of their wishes and feelings on donation, or evidence that donation would be consistent with their beliefs and values. Most child potential donors are likely to fall into category (vii) with consent provided by someone with parental responsibility.

### Organ donation under the Human Tissue (Scotland) Act 2006

4 In Scotland, the Human Tissue (Scotland) Act 2006 uses the term "authorisation" rather than "consent". In its treatment of children, it makes a distinction between those aged 12 or over, and those under 12. While those under the age of 12 are not permitted to authorise donation, the Act explicitly states that a child aged 12 or over can provide authorisation for donation in their own right.<sup>28</sup>

In the case of a child, either:

- a. authorisation for donation after death is available from the donor child (aged 12 or over),  
or
- b. authorisation for donation after the donor child's death will be provided by someone who had parental responsibilities and parental rights for the child (usually a parent; local authorities are specifically excluded).

- 5 Both categories will include a spectrum of possibilities. The first category will include: (i) donors who have both authorised donation and agreed to undergo some or all procedures which would increase the probability of a successful transplant; (ii) donors who have simply authorised donation by joining the Organ Donor Register or signing a donor card; and (iii) donors who have authorised donation without performing one of the formalities in (ii).
- 6 Within the second category (4b. above), a person may not provide authorisation if they have “actual knowledge that the child was unwilling for any part of the child’s body, or the part in question, to be used for transplantation”<sup>29</sup>. Cases in this category could therefore encompass: (iv) donors who have authorised donation, but agreement is nonetheless sought from someone with parental rights and parental responsibilities; (v) donors for whom authorisation is provided on the basis of their wishes and feelings; (vi) donors for whom authorisation is provided on the basis of the beliefs and values that would be likely to influence their decision; and (vii) donors for whom authorisation is provided even though there is little or no evidence of their wishes and feelings on donation, or evidence that donation would be consistent with their beliefs and values. Most child potential donors are likely to fall into category (vii) with authorisation provided by someone with parental rights and parental responsibilities.

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10. Children Act 1989, s.1; Children (Scotland) Act 1995, s.1.
11. Portsmouth Hospitals NHS Trust v Wyatt [2005] EWCA Civ 1181, [87]. See also, General Medical Council. 0-18 Years: *Guidance for all Doctors*. 2007, [12].
12. UK Donation Ethics Committee. *An Ethical Framework for Controlled Donation after Circulatory Death*. 2011, sections 1.3 and 1.4.
13. “Gillick competent” in England, Wales & Northern Ireland. In Scotland, the test for capacity is found in the Age of Legal Capacity (Scotland) Act 1991, s.2(4). The child must be aged 12 or over to provide authorisation in Scotland. See the Appendix for more detail.
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18. General Medical Council. *0-18 years: guidance for all doctors*. 2007, [37(a)]. This test is also used by the GMC in relation to parents' access to their child's medical records at [54].
19. "Parental consent will probably not be valid if it is given against the child's interests. This means that parents can consent to research procedures that are intended directly to benefit the child, but that research that does not come into this category can only be validly consented to if the risks are sufficiently small to mean that the research can be reasonably said not to go against the child's interests." Royal College of Paediatrics & Child Health. *Guidelines for the ethical conduct of research involving children*. *Arch Dis Child* 2000;82:177-182.
20. *S v S* [1972] AC 24, confirmed more recently by the Court of Appeal in *Re H (paternity: blood test)* [1997] Fam 89, and cited with approval by the Inner House in *Docherty v McGlynn* [1983] SLT 645. For more on the application of the 'not against the interests' test in relation to medical treatment for children in Scottish law, see Thomson J. *Family Law in Scotland* (Bloomsbury, 2011) 269.
21. Academy of Medical Royal Colleges. *A Code of Practice for the Diagnosis and Confirmation of Death*. 2008. 28.
22. Brierley J. Neonatal organ donation: has the time come? *Arch Dis Child Fetal Neonatal Ed* 2011;96(2):F80-3.
23. NHS Blood & Transplant. *Organ Donation and Transplantation Activity: Annual data for financial years 2009/10 to 2013/14 (United Kingdom)*. 2014.
24. Parisi F, Squitieri C, Carotti A, Di Carlo D, and Gagliardi MG. Heart transplantation on the first day of life from an anencephalic donor. *Pediatric Transplant* 1999;3:150-151.
25. Royal College of Pathologists & Royal College of Paediatrics and Child Health. *Sudden unexpected death in infancy*. 2004. Appendix III.
26. Human Tissue Authority. *Code of practice 2: Donation of solid organs for transplantation*. 2009, [115]: 'The position for a child, who was competent to reach a decision before they died and consented to organ donation taking place after their death, is legally no different from that of an adult. The child's consent is sufficient to make the removal, storage or use of their organs for transplantation lawful.'
27. Human Tissue Authority. *Code of practice 2: Donation of solid organs for transplantation*. 2009, [116]: 'Clearly, in any case where a child has given consent to donation, especially if the child has self-registered on the ODR [Organ Donor Register], it is essential to discuss this with the child's family, and take their views and wishes into account before deciding how to proceed. In some cases it may also be advisable to discuss with the person who had parental responsibility for the deceased child, whether the child was competent to make the decision.'

28. Provided the child has the capacity to decide for themselves as determined using the test for capacity in the Age of Legal Capacity (Scotland) Act 1991, s.2(4).
29. Human Tissue (Scotland) Act 2006, s.9(4)(a).

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