



Topic Expert Group: Ethical decision-making and palliative care

Rights of infants, parents, and families in difficult decisions

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Target group

Infants, parents, and families

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard

The rights of infants, parents, and families in difficult decisions are respected by healthcare professionals. The values behind any decisions that may compromise those rights are transparent.

Rationale

The goal of this standard is to ensure that decisions respect the rights of children, parents, and families as far as this is feasible. For infants, the relevant rights related to treatment and care decisions are: The right to a human identity, care and nurture, association with parents, freedom from discrimination and from unnecessary pain. (1,2) The infant is an individual in its own right, but also a child in the custody of the parents and born into a wider family and into a society. (3) When infants are malformed, injured at birth, born preterm or ill and depend on special care for their comfort or survival, then the infant is particularly vulnerable and dependent on help. The family may be in acute psychological and social distress, increasing their vulnerability. This places an ethical duty on healthcare professionals to protect the integrity, dignity and comfort of the infants and their family, as well as supporting the autonomy of parents in their execution of parental custody. There is also a duty to protect privacy, promote equity and prevent discrimination, particularly when discussing ethical issues. (4)

Benefits

- Best possible care is provided to infants that is aligned with their clinical situation and therapeutic goals set for them (consensus)
- Increased trust of parents and families that their rights are respected (consensus)
- Increased transparency allows an open discussion of issues (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents and family are informed by healthcare professionals about the	B (High quality) C (High quality)	Patient information sheet



standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter or national equivalents. (1)

For healthcare professionals

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|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------|------------------|
| 2. The standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter or national equivalents are adhered to by all healthcare professionals. (1) | B (High quality)
C (High quality) | Parent feedback |
| 3. The best interests of infants and wishes of parents are respected. There is no discrimination because of age, race, religion, beliefs, gender, or sexual orientation. (1) | B (High quality)
C (High quality) | Parent feedback |
| 4. When the best interests of infants or wishes of parents or families cannot be met the reasons are explicitly documented. | B (Low quality) | Clinical records |

For neonatal unit

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|-----------------------------------------------------------------------------------------------------------------|-----------------|--------------|
| 5. The adequacy of clinical services for infants is reviewed at regular intervals and any shortcoming declared. | B (Low quality) | Audit report |
|-----------------------------------------------------------------------------------------------------------------|-----------------|--------------|

For hospital

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|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|--------------|
| 6. The standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter or national equivalents are ensured. | B (High quality) | Audit report |
| 7. The distribution of resources among services for different groups of patients is reviewed at regular intervals to address questions of equity and to prevent discrimination. | B (Low quality) | Audit report |

For health service

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| 8. Rights of infants, parents, and families are included in the Curricula of the healthcare professional education. (see TEG Education & training) | B (High quality) | Training documentation |
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Where to go – further development of care

Further development	Grading of evidence
For parents and family N/A	
For healthcare professionals N/A	
For neonatal unit N/A	
For hospital N/A	
For health service N/A	

Getting started

Initial steps
For parents and family <ul style="list-style-type: none">• Parents and family are verbally informed by healthcare professionals about the standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter or national equivalents. (1)• Encourage hospitals to adopt the UN Convention on the Rights of the Child. (1)
For healthcare professionals <ul style="list-style-type: none">• Audit service against the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents.• Identify solutions where rights are compromised.
For neonatal unit <ul style="list-style-type: none">• Develop information material about the standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents for parents.• Audit service against the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents.• Identify solutions where rights are compromised.
For hospital <ul style="list-style-type: none">• Audit service against the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents.• Identify solutions where rights are compromised.
For health service <ul style="list-style-type: none">• Incorporate the UN Convention on the Rights of the Child (1) in the Curricula of the healthcare professional education. (see TEG Education & training)

Source

1. UNICEF. The United Nations Convention on the Rights of the Child [Internet]. 1990. Available from: https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.163550268.1218459234.1527076484-403558301.1527076484



2. Council of Europe. Guidelines on child-friendly health care. 2011; Available from: https://www.each-for-sick-children.org/images/2015/Council_of_Europe_guidelines_on_child-friendly_health_care.pdf
3. Council of Europe. The best interests of the child; a dialogue between theory and practice [Internet]. 2016 [cited 2018 May 23]. Available from: <https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=0900001680657e56>
4. Latour JM, Albarran JW. Privacy, dignity and confidentiality: a time to reflect on practice. *Nurs Crit Care*. 2012 Jun;17(3):109–11.

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Lifecycle

5 years/next revision: 2023

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