

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

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Question 1

Where there is evidence from RCT's / meta-analysis that the measures have a strong likelihood of significantly improving the outcome. There are circumstances when it would be appropriate to override the wishes of the pregnant woman. This is where there is only a very small chance of survival and/or survival would result in a very high chance of severe disability. It is important that the parents are always fully informed and it is confirmed by documentation that they understand the situation.

Question 2

1, 3 & 4 When the baby is extremely premature < 25 weeks gestation
When the baby has poor prospects of survival and poor prospects of quality survival
Quality of survival needs to be better defined
When the baby has acquired brain damage and is considered to be highly likely to have severe disabilities in later life

Question 3

Yes Whether parents are entitled to demand action or inaction and/or what their rights are should they choose to do so

Question 4

Yes How do personal/life events influences affect parental decisions? How can parents best feel or know their views are being /have been considered?

Question 5

The child's parents, their extended family, the children when they are considered old enough or capable enough to give a view, their community, parents/groups of parents of severely disabled children, medical or nursing staff involved in care of disabled children, an ethical group such as yourselves (rather than a local ethical committee) The views of the parents together and the family should carry the most weight in the knowledge and assurance that the family have been fully informed of the situation and likely outcome. This could be via an independent body/person with experience in these matters using a body such as yourselves as a reference point The doctor caring for the child should also be involved. Such decisions could be made as above with the opportunity offered for parents to ask for a second opinion from a person/body with experience in this area The law should only be used after a process such as the above has been documented to have taken place

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Question 7

No

Question 6

Economic considerations could be used where the chance of a prolonged time in intensive care is high and an outcome without severe disability is low. Data can be obtained on this in the case of extremely premature newborns. Cost should not be the primary consideration but could be an additional factor to consider. Information from the Netherlands on this issue may assist healthcare providers in deciding on the babies where it is recommended a discussion with the parents should take place.

Question 8

Yes. Yes. A minimum gestation should be decided on (with opportunity for review at regular intervals) below which it should mandatory that a discussion takes place in the format suggested above in the other answers. Below this gestation it might be better worded to state that instituting intensive care is not the normal recommended procedure rather than would not normally be permitted

Question 9

I remain unsure on this. The UK usually operates on a case law basis so advice from leaders in this field may be helpful but legislation may not be.