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.

Mr Kevin Power, Principal Lecturer

QUESTIONS ANSWERED:

Question 1
Any action to sustain life/correct abnormalities must carry a balance between the benefit to the child and the risk of premature birth as a result of the intervention. It must also be clear that the intervention is being carried out for the benefit of the child rather than merely to relieve the potential burden to the parents/family of caring for a disabled child. This should only occur where a) the fetus has established rights as an entity and b) the mother lacks capacity to make a competent decision

Question 2
When the baby is extremely premature. There needs to be a judgement regarding the prognosis for a premature neonate, a simple gestational time limit is unlikely to be applicable to all neonates and if publicised may result in parents lying about dates of conception in order to secure intervehntion. When the baby has congential abnormalities. Similarly there should not be an assumption that all neonates with the same congentital abnormality have the same life chances and a judgement would need to be made regarding the potential benefit vs. harm of prolonging life. When the baby has poor prospect of survival. Medicine and surgery should only be used in palliation in these circumstances not just to prolong a life where there are poor prospects of survival beyond infancy. When the baby has acquired brain damage. As above

Question 3
The moral status of the fetus is central to the ethical questions that should be considered because if there is no moral status all other questions become redundant. questions 2 & 3 are also important for consideration. There should also be some consideration of justice for the baby, both in terms of upholding the moral rights of the infant and (in the climate of resource limited services) fair distribution of resources.

Question 4
These are all important questions. There should also be questions regarding the balance between parents and professionals in the decision making process. Social questions must include how can sociaety be organised better to take account of the needs of those who may be disabled due to problems in utero/in the neonatal period.

Question 5

No one person can best judge the quality of life for a child. The child is best able to judge their own quality but this is limited by their ability to communicate that to others. The family of the child should be in a strong position to judge the child's quality of life but will need help to ensure they are not overly influenced by any concerns regarding the impact the child would have on their own life. However this must be a consideration. Where a family has a relationship with a religious/spiritual counsel/advisor/friend this person should be involved to help in decision making. An independant advocate to speak on behalf of the fetus/infant should also be involved. The law should only be used to challenge decisions regarding best interests of the fetus/infant. Medical advice should be part of the decision not the full story. Clinical ethics committees could resolve a lot of the disagreements regarding the medical opinions of a case.

Question 6

Economic considerations are necessary since health services are resource limited and there are competing interests for those resources. This should not however be a prime consideration but part of the overall analysis of the benefits of initiating or continuing with an intervention or programme of interventions. This should not however be centred on an individual child but used to establish a set of criteria by which decisions can be guided. Thus where a set of criteria are met by an individual fetus/infant that indicate an imbalance of resource expenditure and potential benefit there might need to be strong justification for initiating/continuing interventions with that fetus/infant.

Question 7

All individuals should count as one and thus a year of an infants life is as valuable as a year of an elderly persons life. Age based criterion are inherently discriminative without a sound moral basis for such discrimination. Thus the weightings for any health gain measure should emain the same throughout the life span.

Question 8

Clear guidance is needed but this should not be over directive as this will stifle professional ethical debate. It is imperative that debate continues to ensure that all parties can appreciate that there may be valid moral arguments both for and against a position that might be adopted. To be too directive would imply there is the possibility of a correct resolution to a problem. There should be a minimum age below which cardiopulmonary resuscitation should not be permitted but this should be reviewed regularly in the light of new advances in care/treatment. There should be

clear guidance regarding what constitutes resuscitation to distinguish between fluid replacement and full CPR.

Question 9

This may be helpful to those who are desirous of some directives regarding these issues but this is likely to lead to challenges in the courts when clinicians are seen to rigidly impose legal directives.