

Chapter

9

Conclusions and
recommendations

Conclusions and recommendations

Introduction

- 9.1 Scientific and medical developments in fetal and neonatal medicine have enabled children who previously would have died to survive and lead healthy and fulfilling lives. These same developments have also created ethical, social and legal dilemmas for those families and health professionals who are faced with making complex and emotionally demanding decisions that may have lifelong consequences. In our deliberations, we have found that the difficult questions that arise in fetal and neonatal medicine concern a number of recurring ethical issues. These include the nature and value of human life at different stages of development, distinctions between the active ending of life and death resulting from withholding or withdrawing treatment, and balancing the interests of affected children, their families and the needs of other social groups (paragraphs 2.28–2.30). All too often there is substantial disagreement about these issues and how they should be resolved. Within the Working Party, members themselves hold diverse opinions on these matters. Thus one of our challenges has been to consider, given that people hold morally diverse views, how we can arrive at sensible judgements on which to base public policy.
- 9.2 The title of our Report, *Critical Care Decisions in Fetal and Neonatal Medicine* reflects our central concern with decision making. We endorse wholly the ideal of a ‘*partnership of care*’ advanced by the RCPCH and BAPM (paragraph 2.48). In some cases, it may be that the essence of the question to be decided is what *ought* to be done. In many instances, there will not be an answer that is clearly right or wrong. Reasonable people could disagree. In this Report we often focus on not so much *what* is the ‘right’ decision, but on *how* a decision should be arrived at and *who* should make the decision. To do so, we need to know how such decisions are currently made. The fetus and the newborn baby cannot speak for themselves. Who speaks for them, and how their interests are identified and protected, are crucial questions for us.
- 9.3 All decisions, whoever makes them and however they are made, depend on adequate and accessible information. Insufficient or contradictory information impairs the decision-making process. The quality of the information and data available to professionals, families and policy makers in this challenging field is frequently inadequate or incomplete. This means that uncertainty affects many of the critical decisions that may arise in both fetal and neonatal medicine. One example is imprecision in identifying the long-term outcome for a baby in poor health. While neonatologists can offer families some information about the statistical probabilities of their extremely premature or very ill baby surviving, and the likelihood that he or she will be affected by some disability, they are limited in what they can predict for that particular baby. The paucity of information hinders doctors from answering the question that all parents ask, which is ‘what will happen to *my* baby?’.
- 9.4 Decisions in fetal and neonatal medicine such as whether to intervene to prolong life, or to withhold or withdraw certain forms of treatment arouse strong emotions. Emotional influences upon decision making must be recognised and respected both in clinical decisions about individual babies, and in national policy making. Strong emotional reactions are also aroused by questions about a fetus’ claim to rights, and perceptions of disability and disabled people. Such reactions are not confined to people with direct experience of these dilemmas. Personal experience, professional and social background, religious and cultural perspectives all play a role in forming people’s views and cannot be ignored. The Working Party has been struck by how practice varies in resolving similar dilemmas in neonatal medicine in different hospitals in the UK, and also between the UK and other countries. We begin our final discussion by presenting our conclusions and recommendations on fetal medicine, the borderline of

viability, and decisions about other babies in intensive care. We then turn to decision making, determining best interests and the resolution of disagreement. After providing our views on economic considerations and the lifelong needs of children with disabilities, we conclude by identifying needs for monitoring and research, information, education and training.

Fetal medicine

- 9.5 Members of the Working Party hold a range of different views on the moral status of the fetus, a reflection of the diversity of moral opinion among people in the UK, which is in some cases linked to religious belief. Collectively, however, **the Working Party regards the moment of birth, which is straightforward to identify, and usually represents a significant threshold in potential viability, as the significant moral and legal point of transition for judgements about preserving life (see paragraph 2.19).**
- 9.6 **We consider that a pregnant woman who has chosen to continue her pregnancy has strong ethical obligations to protect the health of the future child.¹ We are not persuaded, however, that the law should require pregnant women to submit to medical or surgical interventions to benefit a fetus against their will (see paragraph 2.20).** Women whose conduct in pregnancy compromises the health of their child should not be subject to legal sanctions. The unique context of pregnancy is such that legal intervention to compel pregnant women to comply with medical advice would involve an unjustifiable invasion of their bodily integrity and liberty demanded of no other citizen. Nor would such sanctions be likely to achieve the desired benefit to the fetus. It is our view that sanctions would be unjustifiable and impracticable, and could not be related exclusively to the context of critical care decision making.
- 9.7 **We endorse the current position in the UK whereby decisions about interventions to benefit the fetus, including the mode and timing of delivery, are made only with the consent of the pregnant woman, and that she should determine what happens in cases of dispute with her partner or her obstetrician (unless her mental capacity is impaired). Women making such decisions must be provided with comprehensive, accessible information on the risks and benefits of what is proposed, and (where possible) enabled to make their decisions with the support of their partners, their wider family or others they would like to consult, should they so wish (see paragraphs 8.4–8.5).** Emotional and social support are particularly crucial where a woman's lifestyle puts the health of the fetus or future child at risk because she has a serious infection or because she is addicted to drugs or alcohol.
- 9.8 The Working Party is aware of the development of open fetal surgery as a possible means of correcting or lessening the impact of some abnormalities but believes that the value of such procedures remains unclear at this time. Such procedures carry a high risk to the pregnant woman and the outcomes reported to date have been generally poor or worse than operations performed after birth. **The view of the Working Party is that in the UK, new procedures in fetal surgery should be offered only within a protocol approved by a research ethics committee (see paragraph 4.11).** There should also be careful scrutiny of the potential benefits and harms of new procedures.
- 9.9 This Report addresses decisions on the critical care of fetuses at risk of developing serious conditions that are likely to compromise the prospect of live birth or to impair the health of the baby once born. Except where fetal treatment is possible, the options for a pregnant woman

¹ In the context of this Report, ethical issues arise in situations where it may be possible to treat a fetus with medicine or surgery but the pregnant woman does not give her consent (see Chapter 4, Case 1). More general circumstances of where a woman could risk the health of her future child are, for example, when a mother is HIV-positive but does not accept treatment, or when she does not modify her addictive drug-taking behaviour during pregnancy.

in this situation are between early delivery, terminating or continuing the pregnancy (paragraph 4.12). Termination of pregnancy in such cases is lawful under the Abortion Act 1967 s. 1 (1) (d) (as amended), on the grounds that “there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped”. The Working Party is aware that there are calls to reduce the time limit for lawful termination of pregnancy for what are often called ‘social abortions’ below the current 24 week limit, primarily in response to the increased survival rates of premature babies below this gestation. Provided termination on grounds of fetal abnormality after any reduced time limit would still be permitted, the kinds of decision making that we examine in this Report would not be affected. Therefore we do not take a position on this issue.

- 9.10 The late termination of pregnancy and feticide are controversial (see paragraphs 4.14–4.16). We recommend that there should be greater uniformity of practice and interpretation of the law in relation to feticide. Additionally we note that it is incorrect to interpret the law as requiring all possible measures to be taken to prolong the life of a baby born alive if it is not in his or her best interests. **We recommend that a code of practice be developed for healthcare professionals to achieve clarity about what the law does and does not require doctors to do. Such a code would also help ensure that pregnant women are given sufficient information about possible outcomes if a baby is born alive following termination on grounds of fetal abnormality. It would reassure doctors should a woman choose not to consent to feticide. The responsibility for developing the code of practice should be taken by a broad group of professional organisations² consulting as appropriate. Where relevant, the code should be made available to a woman as part of her care pathway (see paragraph 8.8).**³

Borderline of viability

- 9.11 We have endorsed birth as the crucial legal and moral threshold so that once ‘born alive’, a newborn baby has the same legal status and entitlement to respect as older children or adults. The Working Party found, however, that in the context of what can now be achieved with intensive care, legal definitions of what it means to be born alive are imprecise. A baby after 24 weeks of gestation is defined as stillborn (dead) if he or she does not breathe or show any signs of life. However, such a baby may be entirely capable of survival provided he or she is given immediate assistance with breathing. Equally, a baby about to die from a condition that is incompatible with life may nevertheless breathe for a few moments. There exists no single precise definition in use as to what constitutes ‘born alive’. **We therefore recommend that the RCOG and RCPCH, together with BAPM and the Royal College of Midwives (RCM), should consult widely and develop a definition of ‘born alive’ which encompasses the capacity of the baby to breathe either independently, or with the support of a ventilator. Consideration should be given to incorporating such a definition in statute (see paragraphs 8.13–8.16).**
- 9.12 Once a baby is ‘born alive’, the parents and the healthcare professionals in the hospital where he or she is delivered owe the baby a duty of care. Parents have interests and these must be accorded some weight. However, decisions about the care of a baby concern his or her future existence and quality of life, and the baby’s interests in these naturally carry very great

² We suggest that these might include the RCOG, the RCPCH, the Royal College of Midwives (RCM), the RCN and the Neonatal Nurses Association.

³ The *National Service Framework (NSF) for Children, Young People and Maternity Services* recommends that women should make informed choices and plan their care in partnership with professionals and that a woman should have easy access to information and support throughout her pregnancy. The NSF is based on an approach where care pathways are used to illustrate a woman’s progress through the available pregnancy services. See Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 17 July 2006.

weight. **The Working Party concludes that the best interests of a baby must be a central consideration in determining whether and how to treat him or her (see paragraph 2.21).** The extent to which parents are consulted in advance about the initiation of intensive care appears to vary across the UK. **We strongly endorse the recommendations of the RCPCH and BAPM that, wherever possible, when the birth of a baby who is extremely premature or who is affected by significant abnormalities is expected, before the birth an experienced neonatologist should discuss options for admission to intensive care. We encourage the Royal Colleges and the NHS to find ways to foster a common approach by obstetricians, midwives, nurses and neonatologists.**

- 9.13 Current practice in most neonatal units in the UK is usually to resuscitate a baby if the outcome is uncertain and to institute intensive care until the outlook is clearer. There is no legal obligation to provide life-sustaining treatment where parents and professionals are agreed that a baby is unlikely to survive and/or suffers from such severe abnormalities as to render it not in his or her best interests to be offered invasive intensive care. In all circumstances, including when a baby has been delivered early by intention, when a woman has gone spontaneously into premature labour, when a baby is delivered later in pregnancy suffering from severe disabilities, or when a baby is born alive after a lawful termination of pregnancy, the legal obligation is to provide *appropriate* care. Such care does not necessarily include admission to a neonatal intensive care unit (see paragraphs 8.8 and 8.17).
- 9.14 Decisions to initiate life support are especially problematic where a baby is delivered before 24 weeks of gestation because there is a high probability that the baby will die or develop some level of disability, and great uncertainty about whether treatment is in the best interests of a baby should he or she survive. We consider that babies should not be subjected to intensive interventions that are not likely to have any benefit and which may cause suffering. We have given careful consideration to whether resuscitation and intensive care should be withheld from babies born below a stipulated number of weeks of gestation or a particular birthweight. Guidelines operating in the Netherlands recommend that babies of less than 25 weeks of gestation should not be resuscitated (see Box 8.1). **We do not regard this as an appropriate matter for legislation in the UK.** We consider any complete ban upon resuscitation and continuation of intensive care to be an unjustifiable infringement of the interests of both the child and the parents, and professional responsibilities. For similar reasons we reject any absolute limit below which resuscitation is not permitted, in view of the considerable variability in outcome for babies born at the same very early age of gestation, and the possibility of variation in estimates of gestational age by up to five days (see paragraphs 2.56–2.57 and 5.4). **However, we do believe that clearer guidance would be helpful to both parents and professionals.** More clarity would assist parents in reaching a better understanding of the uncertainties about their baby's ability to survive, and subsequent state of health. It would also benefit less experienced doctors in labour wards and neonatal units when circumstances dictate that decisions on resuscitation have to be made in the absence of a senior doctor (see paragraph 8.26). It is our view that explicit guidelines will encourage more openness, greater consistency in practice and firmer expectations for parents.
- 9.15 Evidence demonstrates that the outcome of intensive neonatal care when babies are born before 24 weeks of gestation is likely to be poor (see Table 5.1). Based upon current data, if a baby is delivered before 22 weeks, six days of gestation, survival is highly unlikely. Prolonged periods of stressful and invasive treatment are likely to be required if a baby of this gestational age is to survive. In the EPICure study of children born in 1995 in the UK and Ireland, approximately 10% of the babies who were born with signs of life at 23 weeks survived to the age of six. Five out of 22 survivors born at 23 weeks of gestation were later assessed as having severe disability and eight were free from moderate or severe disabilities (see Table 5.1). It must therefore be questioned whether it is in the best interests of a baby to be subjected

to the burdens of invasive intensive care. Any presumption that the best course of action is to initiate intensive care and then to withdraw it if the prognosis is poor must take into account the uncertainty over outcomes that follow birth at such early stages of gestation. Clarity about the chances of abnormalities likely to produce later serious disability may not develop or be detected until a baby's condition improves and intensive care is no longer required. **We have concluded that there is no reason to distinguish between withdrawing treatment and deciding not to start it, provided the decision is made in the best interests of a baby (paragraph 2.33).** We acknowledge, however, that decisions to withdraw intensive care, once initiated, may be exceptionally distressing for families and healthcare staff, and that they may perceive a moral difference. Given this situation, our view is that greater clarity on whether to initiate full intensive care might be helpful. **We therefore recommend that the RCPCH and BAPM, together with the RCOG, RCM, RCN and other associated professional bodies, should consider the development of guidelines for deciding to institute full intensive care for babies born below 26 weeks of gestation, consulting as appropriate, including with groups that advocate for parents.⁴ We propose below a set of guidelines to provide a basis of discussion by these bodies.**

Proposed guidelines for deciding to institute intensive care

9.16 The guidance for deciding to institute resuscitation and full intensive care should include:

- (a) An experienced paediatrician should be present at the delivery and make a confirmatory assessment of the gestational age and condition of the baby.**
- (b) At 25 weeks of gestation and above, the relatively high rate of survival and the relatively low risk of severe disability are such that intensive care should be initiated and a baby admitted to a neonatal intensive care unit, unless he or she is known to be affected by some severe abnormality incompatible with any significant period of survival.**

Below 25 weeks of gestation, where the delivery of an extremely premature baby is anticipated and circumstances permit, the clinical team should discuss with the parents in a thorough and frank fashion, the national and local statistical evidence for survival and the range of disabilities which are indicated for this age group. In the consultation with the parents, the healthcare team should make it clear that statistics indicate that most babies born below 25 weeks of gestation will die.

- (c) Between 24 weeks, 0 days and 24 weeks, six days of gestation, normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit, *unless* the parents and the clinicians are agreed that in the light of the baby's condition (or likely condition) it is not in his or her best interests to start intensive care.**
- (d) Between 23 weeks, 0 days and 23 weeks, six days of gestation, it is very difficult to predict the future outcome for an individual baby based on current clinical evidence for babies born at this gestation as a whole. Precedence should be given to the wishes of the parents regarding resuscitation and treatment of**

⁴ Broadly speaking, outcomes for premature babies at the borderline of viability improve with each additional week of gestational age. We intend our proposed week-by-week guidelines to be sufficiently flexible to take account of the variation in (1) how babies of the same age respond to treatment and (2) estimates of gestational age confirmed by ultrasound analysis, which are accurate to within five days (95% of cases) when carried out in the first trimester of pregnancy. We emphasise that a careful prior assessment of each baby and discussion with the parents, before the birth if possible, should precede any action. We recommend (paragraph 9.17) that guidelines should be reviewed regularly and revised, as needed, to reflect any future changes in outcomes.

their baby with invasive intensive care. However, when the condition of a baby indicates that he or she will not survive for long, clinicians are not legally obliged to proceed with treatment wholly contrary to their clinical judgement, if they judge that treatment would be futile (see paragraph 8.32). As a first step, it will be necessary to determine whether a baby is suffering, whether any suffering can be alleviated, and the likely burden placed on the baby by intensive care treatment (see paragraph 9.32). Where parents would prefer that the clinical team made the decision about whether or not to initiate intensive care, the clinicians should determine what constitutes appropriate care for that particular baby. Where there has not been an opportunity to discuss a baby's treatment with the mother (and where appropriate her partner) prior to the birth, the clinical team should consider offering full invasive intensive care until a baby's condition and treatment can be discussed with the parents.

- (e) Between 22 weeks, 0 days and 22 weeks, six days of gestation, standard practice should be not to resuscitate a baby. Resuscitation would normally *not* be considered or proposed. Only if parents request resuscitation, and reiterate this request, after thorough discussion with an experienced paediatrician about the risks and long-term outcomes, should resuscitation be attempted and intensive care be offered. The treating clinicians must concur that this is an exceptional case where resuscitation is in a baby's best interests.**
- (f) Below 22 weeks of gestation, no baby should be resuscitated, except in the situation described below in paragraph 9.19.**
- (g) When intensive care is not given, the clinical team should provide palliative care until the baby dies.**

9.17 At the time of writing, most babies born at 23 weeks die or survive with some level of disability even if intensive care is given. Survival and discharge from intensive care for babies born between 22 and 23 weeks is rare. It is natural that parents may hope that their exceptionally premature baby will survive against the odds. We have no evidence of any therapeutic developments likely to improve the prospects of survival for babies born before 22 weeks in the near future. The nature of clinical advance is for doctors to seek to extend the boundaries of medicine but it is our view that caution is currently required over decisions to treat babies born up to 23 weeks, six days of gestation. **We recommend that should professional bodies choose to produce guidelines for instituting intensive care, these should be reviewed regularly and revised to reflect any changes in outcomes for extremely premature babies.**

9.18 According to our proposed guidelines, parents could refuse intensive care for their baby if he or she is born between 23 weeks and 23 weeks, six days of gestation. Because it will be the parents who live with the consequences of any decisions to resuscitate at the limits of viability, we consider parental informed consent to be especially important for decisions to use life support for babies born at this age of gestation. If a pregnant woman is unable to consent before the birth because of her clinical condition, doctors should resuscitate the baby. Similarly after birth if the mother is unable to consent or if the parents should disagree, resuscitation should again proceed. Once a baby is born, a mother no longer has exclusive responsibility for decision making. For birth below 23 weeks, normal practice would be not to resuscitate a baby.

9.19 Below 22 weeks of gestation, we consider current attempts to resuscitate a baby to be experimental. Any attempt to resuscitate babies born at this gestational age should take place only within the context of an approved research study within which the parents understand that their baby is participating in a particular project. Research may improve outcomes for babies in the future, but is highly unlikely to improve the outcome for those babies participating in

a study. **On the evidence available to us, we therefore recommend that, unless and until documented scientific evidence establishes realistic prospects that babies born at or before 21 weeks, six days could survive to be discharged from intensive care without developing severe disabilities, attempts to resuscitate these babies should *only* take place within a clinical research study that has been assessed and approved by a research ethics committee and with informed parental consent (see paragraph 5.13).**

Critical care decisions for babies needing intensive care

9.20 After resuscitation or admission to intensive care, it may be discovered that a baby has such profound abnormalities or his or her condition has so deteriorated that prolonging life is considered by the clinical team to be futile. Decisions will have to be made about whether to continue ventilation and other intensive care, or to offer only palliative care to alleviate pain and distress. In the UK, it constitutes neither murder nor manslaughter to cease interventions to prolong life when such measures are very unlikely to succeed and are unduly burdensome to a baby (see paragraph 8.17). We have considered carefully whether the law should be reformed to allow doctors to end the life of a baby in these circumstances, assuming that this could be done swiftly and painlessly, for example, by means of a lethal injection. Members of the Working Party held different views about whether it can ever be permissible to take active measures to end any human life. Some members would reject such measures as intrinsically unethical in any circumstances while others would consider such measures to be acceptable in principle, under certain restricted conditions. These conditions would be when a baby was enduring extreme suffering or his or her life was intolerable in other ways (see paragraph 2.16). The Working Party was aware that the latter view commands some support⁵, and that actively ending the life of a newborn baby is now sanctioned in the Netherlands. Our deliberations therefore included the question of whether legislation allowing active steps to end a newborn baby's life should be considered by Parliament. **Despite different personal views on whether any form of active ending of life could ever be ethically justifiable, the Working Party unreservedly rejects the active ending of neonatal life even when we would view that life as 'intolerable' (see paragraphs 2.16 and 2.37). Furthermore, we unanimously rejected the notion that there should be a law or laws expressly and exclusively allowing ending the life of newborn babies.**

9.21 From an ethical perspective, we drew a moral distinction between, on the one hand, withholding or withdrawing life-saving treatment, and on the other, actively ending the life of a baby, for reasons based on the moral responsibility of doctors and the need for ethical consistency. Many doctors are clear that they have a professional obligation to preserve life where and when they can and further, they would not be prepared to act expressly to end the lives of babies in their care. It would therefore be unacceptable to many doctors, for example, actively to take life. Furthermore, permitting doctors deliberately to end life would be likely to have a negative psychological impact, both in personal terms and from erosion of trust in the medical profession. In terms of ethical consistency, rejection of adult euthanasia while permitting the active ending of the life of a newborn baby whose life is intolerable would require demonstration of a morally relevant difference between a newborn baby and adults who are unable to consent for themselves.

9.22 From a legal perspective, we concluded that legislation permitting doctors to decide to end the lives of newborn babies without the consent of the parents would be unacceptable in the UK. We could envisage only very limited circumstances where a parent might even consider

⁵ For a presentation of arguments for the active ending of life in adults, see, for example, Doyal L (2006) Dignity in dying should include the legalization of non-voluntary euthanasia *Clinical Ethics* 1: 65–7.

giving consent. Finally, while in theory it would be possible to frame stringent conditions governing the circumstances in which it was permissible actively to end the life of a baby, we identified a number of objections that might make framing such legislation difficult. These included the violation of the parents' right to respect for the private and family life guaranteed by the European Convention on Human Rights if ending of life were to be permitted without parental consent, and the impossibility of setting a defensible limit for the period after birth in which ending of life of a baby was legal.⁶

- 9.23 Once a critical care decision has been made to withhold or withdraw treatment for a baby, or where there are no appropriate treatments, palliative care should be provided (see paragraphs 6.18–6.22). This is care that endeavours to relieve pain and distress in order to make the rest of a baby's life as comfortable as possible. In the context of best interests, consideration of whether a baby who is dying should be allowed to suffer led the Working Party to conclude that more could be done in the UK to provide better and more consistent access to palliative care for babies within intensive care units. The benefits of palliative care in the hospital setting are well established. During the process of dying it reduces suffering and makes a baby as comfortable as possible. However, there is little standardisation of provision, so that in the UK palliative techniques are used to a variable degree in the delivery and neonatal intensive care settings. **The Working Party therefore proposes that the NHS, supported by the UK Departments of Health and in conjunction with the relevant professional bodies (for example the RCPCH, BAPM, RCN, Neonatal Nurses Association (NNA) and RCM), should train all neonatologists and neonatology nurses in the basic principles of palliative care so that they are applied when a need is identified. To complement this provision, the NHS should facilitate access to specialist advice in palliative care for complex cases in the same way that specialists would be consulted on complex problems in other areas of medicine.**
- 9.24 We note that in the UK when intensive care is withheld or withdrawn from a baby, oral tube feeding and hydration are sometimes continued. In most cases hunger and dehydration would add to a baby's suffering; however, in babies who have a damaged gut, providing food and hydration would be impossible or would increase suffering. **We therefore conclude that oral nutrition and hydration should only be withheld from a baby when it is clear that providing it causes discomfort and pain, such as when a baby has little functioning bowel due to disease or when death is imminent. The decision should only be taken after careful assessment and as part of a planned programme of palliative care designed to minimise suffering and make the baby as comfortable as possible.**
- 9.25 If the decision is made to provide intensive care for a baby, consideration should be given to his or her continuing developmental needs. The nature and number of procedures performed on babies in these units can make intensive care a painful experience, and the bright and noisy environment can be stressful. There is increasing evidence that newborn babies, including those born prematurely, show responses to painful stimuli and that experiencing painful procedures without pain relief during the neonatal period may be harmful. We understand that current clinical practice in terms of detection of pain and provision of pain relief varies widely across the UK (see paragraphs 6.14–6.17).⁷ **The Working Party believes that the reduction of pain and stress for babies in neonatal units is important and suggests to the UK Departments of Health, the Healthcare Commission and relevant professional**

⁶ Article 8(1) of the European Convention on Human Rights.

⁷ Redshaw M and Hamilton K (2005) *A Survey of Current Neonatal Unit Organisation and Policy: Commissioned by BLISS – The Premature Baby Charity* (Oxford: National Perinatal Epidemiology Unit), available at: http://www.npeu.ox.ac.uk/neonatalunitsurvey/neonatalunitsurvey_downloads/BLISS%20Final%20Report.pdf, accessed on: 18 July 2006.

bodies that measures need to be taken to improve clinical practice through the application of current knowledge about the assessment, prevention and treatment of pain in babies receiving intensive care.⁸ The Working Party also encourages the UK Departments of Health and research funding bodies to support high quality research into the potential developmental effects of neonatal pain and stress and their treatments.

Decision making and best interests

- 9.26 UK law requires that decisions whether to initiate, withhold or withdraw treatment must be made in the best interests of a baby. Reasonable people may disagree on what this means. Healthcare professionals will perceive their infant patient differently from the parents and parents' views may differ on whether or not it is in their baby's interests to die peacefully or to continue to receive life support with an uncertain outcome. Both the law and clinical practice in the UK operate on a presumption in favour of life. The courts have suggested that unless a baby's life is likely to be 'demonstrably awful', his or her clinical care should aim to promote survival. Many people live fulfilled and valuable lives while coping with impairments so profound that others could not contemplate such a life.
- 9.27 Determining what is in the best interests of a newborn baby is difficult. A baby does not yet have developed relationships with the outside world and with others that a child will progressively acquire. By contrast, for the child who becomes critically ill at a later age, his or her parents will be able to have a greater sense of what he or she might view as a worthwhile existence. **We recognised that there are very real difficulties in knowing what is best for a baby. Nevertheless we concluded that the principle of best interests should remain a central one in decision making about newborn babies and children.** Thus, in the course of our deliberations we gave careful consideration to whether it might in some circumstances be in the best interests of a baby for intensive care to be withheld or withdrawn. We concluded that it is not in a baby's best interests to insist on the imposition or continuance of treatment to prolong life when doing so imposes an intolerable burden upon him or her. We sought to describe the features of 'intolerability', at the same time noting that reasonable people may disagree both about what it constitutes and/or when a particular baby's condition meets that condition (paragraphs 2.11–2.16).
- 9.28 We agree that, because they concern his or her very existence and quality of life, the best interests of a baby should be a central consideration and carry the greatest weight. **In according particular weight to the best interests of a baby, we do not view the baby as more important than other persons; rather we view his or her interests in living or dying, or in avoiding an 'intolerable' life (see paragraph 2.30) as more important than the interests that others may have in any significant decisions made about him or her.** Furthermore, to say that the baby's interests are of central importance does not mean his or her interests are the exclusively relevant consideration. Nor can a baby be viewed in isolation from his or her parents. The welfare of the baby is inextricably linked with the ability of the parents to care for and support him or her. The views and feelings of the parents should therefore be accorded considerable weight. Their views carry weight in two different senses. First, in the light of their close bond with the baby, the parents have a strong claim to speak for him or her. Secondly, the potential quality of the life in prospect for the baby is significantly affected by the parents' ability to provide an environment within which he or she can achieve his or her full potential. For this they may require state support.

⁸ We note that the *National Service Framework for Children, Young People and Maternity Services* publishes pain management standards that include babies in neonatal units.

- 9.29 Parents also have interests that are distinct from those of their baby. Caring for a baby with serious disabilities may harm their health, their relationship with a spouse or partner, and the welfare of any existing siblings. Similarly, parents have interests in their own emotional well-being and/or their belief system which may include religious faith. In some cases, parental interests may make it difficult for parents to accept that it is in their baby's best interest for his or her life to be prolonged. For example, the demands on other family members may be perceived as too onerous. In other cases, parental interests may render it equally difficult for parents to accept that it may not be in a baby's best interests to continue to take all measures to keep him or her alive. For example, some parents may interpret their faith as requiring that all life should be preserved, regardless of the futility and demanding nature of treatment. In such cases where there is potential for parental interests to conflict with a baby's interests, these parental interests should not be wholly disregarded but should carry much less weight than those parental interests directly addressing the welfare of the baby. **The Working Party is clear that parents have interests and that it is reasonable for these interests to be given some weight in any relevant deliberations about critical care decisions for a baby who has, or who will develop, a serious condition (paragraph 2.29). Furthermore, careful consideration should be given to the interests of all potentially affected persons, who most usually would be other family members who will live with the child and either care for him or her, or themselves depend on the immediate family for support.**
- 9.30 Doctors, nurses and other members of the healthcare team also have interests that may conflict with their ability to represent the best interests of a baby. Their own emotional wellbeing may be affected by carrying out treatments they perceive as futile or by concerns about their additional responsibilities to care for other babies in their charge. Their willingness to accept a different view of the baby's best interests from parents may be influenced accordingly.
- 9.31 **The view of the Working Party is that the current legal principles centred on seeking agreement between parents and professionals as to the best interests of the baby are, in principle, appropriate and that further legislation designed exclusively to address decisions relating to newborn babies alone is not to be recommended.** We doubt that more general legislation introduced to regulate the kinds of decisions that this Report addresses would offer the necessary clarity and predictability to criteria developed in order to judge best interests, since different interpretations of the criteria defined in any possible statute are likely to occur. **However, we propose that clarification of the criteria by which best interests may be judged would be helpful. We therefore develop such criteria below, with the recommendation that they, or similar criteria, should become part of good practice.** These criteria are intended to help parents and professionals alike assess best interests when deciding the threshold for instituting, withholding or withdrawing treatment from newborn babies. The criteria are not weighted in any way. They are intended as a guide and no single criterion should be the sole influence upon decision making. In all cases the important question is whether it is in the best interests of a baby to receive treatment.
- 9.32 **When a decision must be made by doctors whether or not to institute life support and ventilation immediately after birth, the following points should be considered in assessing the best interests of a baby. This assessment should be made in the light of the guidelines for instituting resuscitation and full intensive care proposed above at paragraph 9.16:**
- (a) **The gestational age of the baby at birth.**
 - (b) **The evidence available indicating the likelihood of survival and incidence of severe disability among babies born at that gestational age.**

(c) The evidence available from the initial assessment on:

- (i) the baby's vitality at birth; and*
- (ii) any significant abnormalities.*

(d) The views and feelings of the parents, in the light of that evidence, and accorded the significance proposed above.**9.33 When a decision must be made whether or not to *institute or to withhold further treatment from a baby after birth*, the following questions should be considered:****(a) To what extent is it likely that the treatment in question will effect a significant prolongation of the child's life? (It will not generally be in the interests of the baby to prolong the process of dying).****(b) What degree of pain, suffering and mental distress will the treatment in question inflict on the baby? Will there be a need for repeated, painful and distressing medical interventions? What measures can be taken to ameliorate any pain, suffering and distress?****(c) What benefits will accrue to the future child from the treatment in question, for example:**

- (i) Will the child at any stage be able to survive independently of life support?⁹*
- (ii) Will treatment increase the chance that the child will be able to be cared for out of hospital?*
- (iii) Will the child be likely to be capable of establishing relationships with other people?*
- (iv) Will the child be likely to be able to experience pleasure of any kind?*

(d) Then, in the light of evidence regarding (a)–(c):

- (i) Do the burdens of treatment outweigh the benefits?*
- (ii) What kind of support is likely to be available to provide the optimum care for the child?*

(e) The views and feelings of the parents as to the interests of the baby, especially in relation to (d).

In the rare case that a baby either has no parents or has been taken into care, the local authority will often be able to exercise parental responsibility in relation to that child. However it is important to be assured that the baby's interests are properly represented. This may be a case that would benefit from early referral to a clinical ethics committee (see paragraphs 9.37–9.39).

9.34 When a decision must be made whether or not to *withdraw life-sustaining treatment from a baby with a limited prognosis*, the following questions should be considered:**(a) For how much longer is it likely that the baby will survive if life-sustaining treatment is continued?****(b) What evidence is there that the baby is experiencing pain, suffering or distress? What measures are being, or could be taken, to ameliorate that pain, suffering or distress?**

⁹ We note that with appropriate care, children on long-term ventilatory support can be discharged from hospital. For an example, see *Best Practice Guidance: Care pathway for the discharge and support of children requiring long term ventilation in the community*, National Service Framework for Children, Young People and Maternity Services. This example in turn is taken from Noyes J and Lewis M (2005) *From Hospital to Home: Guidance on discharge management and community support for children using long-term ventilation* (Barnardo's).

(c) Is it likely that, if life-sustaining treatment is continued, the baby will ever be able to survive independently of life support?¹⁰

(d) What benefits accrue to the baby from continuing life-sustaining treatment?

(i) Is he or she able to establish relationships with other people? Does he or she react to his or her surroundings?

(ii) Does he or she experience pleasure of any kind?

(e) In the light of this evidence:

(i) Do the burdens of continued life support outweigh any benefits?

(ii) Does the baby exhibit signs of effort to survive?

(f) The views and feelings of the parents as to the interests of the baby, especially in relation to (e) above.

Disputed decisions

9.35 No matter how clearly any criteria express the basis on which decisions about the care of a baby *should* be made, professionals and parents will sometimes disagree. **As we have said, we endorse wholly the ideal expressed in Guidelines from the RCPCH that a ‘partnership of care’, should be one of the fundamental principles behind decisions on withholding and withdrawal of treatment.**¹¹ However we recognise that there is a need for greater consideration to be given to how disputed cases can be resolved.

9.36 **The Working Party recommends that efforts should continue to be made to resolve disputes about the care of a baby by agreement.** Often this will be possible through further discussions within the neonatal unit. A member of the unit or hospital staff with knowledge of the neonatal unit can often be useful as a facilitator in discussions aimed at reaching agreement. Frequently, parents or clinical staff may simply need more time. There may be misunderstandings or miscommunications that can be resolved with local discussion. **If disagreements remain after further discussion, parents should routinely be offered access to a second medical opinion.**

9.37 There is a perception that the courts are being asked to resolve a growing (though still small) number of disputes.¹² In most (but not all cases) the courts are asked to decide where a dispute arises between those responsible for a baby. We consider that there is a role for a forum to assist parents and professionals making these difficult decisions even when there is no dispute. **We therefore recommend that NHS trusts should explore ways to ensure that all neonatal intensive care units have rapid access to a clinical ethics committee, available to families and staff.** Such committees can play a crucial role in resolving the different views held by parties in dispute, and in developing local guidelines appropriate for the community served by the neonatal intensive care unit (see paragraphs 8.48–8.49).

9.38 In the UK, clinical ethics committees are still at an early stage of development. We anticipate that adaptation of existing models will be required and that new committees may have to be set up to ensure that all units have access. Emphasis should be placed upon fostering common approaches in fetal and neonatal medicine and upon consultation with parents.¹³ The NHS is primarily responsible for providing this service to its staff and customers. **The Working Party recommends that the NHS should identify the best mechanisms for the operation of clinical ethics committees able to provide advice on ethical dilemmas in fetal and**

¹⁰ As footnote 9 above.

¹¹ The other principles listed by RCPCH are the duty of care (under which the parents and healthcare team should enter a ‘partnership of care’ in order to serve the best interests of the child), legal duty and respect for children’s rights.

¹² The Working Party was unable to obtain data because records are not kept in a systematic or centralised way.

¹³ The national Patient Advice and Liaison Service (PALS) is a possible source of contact with parents.

neonatal medicine. The chosen model(s) should be implemented on the basis of equal accessibility for parents and all professionals involved in the health or social welfare of the child. In some cases, clinical ethics committees may be able to play a limited role in resolving disputed cases. Whether a decision is disputed or not, rapid support will be needed if clinical ethics committees are to play an effective role in this area of medicine. **We propose that clinical ethics committees should appoint on-call facilitators for more active resolution of differences in critical care decision making before they become entrenched as a dispute.**

9.39 We consider that misunderstandings lie at the heart of many disputes and that providing routes for swift and effective resolution will be best for all parties. We acknowledge that in a limited number of cases, clinical ethics committees may not be a suitable means of resolving differences. If positions have quickly become deeply entrenched there may be little prospect for resolution. Approaching a committee could even add to frustration or delay the case reaching court. In such cases, we propose that mediation may be beneficial, to help the parties work towards a negotiated agreement of their dispute or difference as an alternative to litigation. The mediator will seek to help the parties to find a 'principled resolution' and remain available to help with follow up, whether or not agreement is reached, and with implementation of any agreement. Even if resolution is ultimately not possible, mediation may improve communication and reduce acrimony, leading to a better mutual understanding of the issues that remain to be resolved by the courts. The substantial human and economic costs of taking a case to court should not be underestimated. **The view of the Working Party is that there are potential advantages to using mediation in disputes about critical care decisions in neonatal medicine. We recommend that the UK Departments of Health should examine the benefits that mediation may offer, with a view to setting up a pilot study to evaluate the possible merits for critical care decision making in neonatal medicine (paragraph 8.62).**

9.40 There will always be cases where resort to the courts cannot be avoided. The European Court of Human Rights made it clear in *Glass v UK* that, except in an emergency, doctors wishing to treat or withhold treatment from a child without parental consent act unlawfully if they act without judicial authority. We can envisage no other forum where all parties would feel confident of a dispassionate and objective ruling and consider that they had been given an adequate opportunity to put their case forward. However, the added ordeal of litigation adds to the responsibility already borne by a baby's parents as well as the professionals involved. Publicity and media coverage can add to that ordeal. There is a trend towards open hearings for disputes about the care of the newborn which is in keeping with a general trend towards more openness within the Family Division of the High Court. This has led to such disputes acquiring a much higher public profile. **We note that as the Family Division moves towards more open hearings, measures will be put in place to protect the privacy of families and professionals if this is their preference. We endorse this plan.**

Economic considerations

9.41 The limitation of resources for healthcare is a major topic of debate in the UK, especially where the lives of babies are at stake. There is now much broader public awareness of the need for difficult choices to be made by the providers of national healthcare. We have discussed the difficult economic issues which have to be managed in neonatal medicine because more babies are able to survive than in the past. We noted that the current national (macro-economic) level of provision of neonatal intensive care does not always meet demand and a baby in need of intensive care may have to be moved hundreds of miles from the hospital in

¹⁴ Work by Dr M Redshaw and Dr K Hamilton published in the BLISS Baby Report 2006.

which he or she was born.¹⁴ Health outcomes may thus be put at risk. Contentiously, this has caused questioning of whether funds spent on resuscitating or prolonging the life of babies where the prognosis is very poor are spent appropriately. Can this be reconciled with the aim of healthcare professionals to treat ‘the baby in front of them’? There is also an overarching issue of how policy makers should allocate finite healthcare resources for the lifelong healthcare needs of a newborn baby starting life at high risk of serious disabilities. **The view of the Working Party is that economic factors must not be the sole consideration in seeking to maximise health benefits. Although by no means exclusive to neonatal medicine, additional principles such as equity and justice should also be taken into account by decision makers (see paragraphs 2.39–2.43).** For example, there remain wide differences in infant mortality between different parts of the country and low birth-weights are more prevalent in lower socioeconomic groups.¹⁵

- 9.42 Supply does not necessarily meet demand. Policy makers and managers responsible for providing resources to neonatal units (the mesoeconomic level of decision making) are aware that comprehensive provision may not be possible without cuts to other services so that, for example, spending more on the very young may reduce the amount available to help the elderly or vice versa. We take the view that policy makers and managers should be fair when distributing resources. We are aware that there is wide-ranging debate, but no consensus, on whether there is any reasonable or fair basis for judging that the age of a patient should be a relevant consideration in any such distribution. We consider that devolution by central government of all responsibility for provision of services to local commissioners is inequitable, as it is unjust that a baby’s chances of receiving appropriate intensive care or subsequent continuing care should depend on where he or she is born. **We conclude that the economic dilemmas posed by the provision of neonatal intensive care highlight the need for a much broader independent analysis of the use of NHS resources, with a view to providing national guidance on allocating resources for healthcare in an efficient and equitable manner.**¹⁶
- 9.43 In the context of fetal and neonatal medicine, decisions at the microeconomic level about critical care of a fetus or baby are made by members of healthcare teams with parents. **At the microeconomic level of decision making, the Working Party recommends that parties should be aware of, but not driven by, the resource implications of their decisions. Such decisions should be determined, not by economic considerations, but by clinical judgements of priority, which take into account the best interests of the babies concerned. Healthcare professionals caring for babies in neonatal intensive care units should therefore continue to do the best possible for the ‘patient in front of them’ (see paragraphs 2.39 and 2.43).**
- 9.44 We have proposed the use of guidelines for the initiation of intensive care in babies for whom critical care decisions need to be made. **We emphasise that our justification for the use of guidelines is not constrained by concerns about limitations on resources. It rests on a judgement about what is in the best interests of a child. Furthermore we wish to reiterate firmly that, just as we find no difference in the moral status of a child of six days, months or years, we find no morally relevant differences between disabled and able-bodied children and adults. Each must be given equal consideration. It is therefore important that all those involved in critical care decisions, especially**

¹⁵ *Ibid.*; Moser K, Li L and Power C J (2003) Social inequalities in low birthweight in England and Wales: trends and implications for future and implications for future population health *J Epidemiol Community Health* 57: 687–91.

¹⁶ We note that the National Institute for Health and Clinical Excellence (NICE) has published guidelines for judgements concerning social values that should be incorporated into processes used to develop NICE guidance. These guidelines are primarily concerned with the judgements that are involved in developing conclusions about cost-effectiveness and particularly those that have implications for priority setting and resource allocation. See National Institute for Health and Clinical Excellence (2005) *Social Value Judgements: Principles for the development of NICE guidance*.

parents, doctors, and nurses, do not feel pressured to allow babies to die because of the risk of disability (paragraph 2.39).

Lifelong support for the disabled child

- 9.45 At the macroeconomic level, any decision to provide intensive care for babies at risk of severe disability if they survive has resource implications beyond the sphere of neonatal medicine. These arise from the costs of caring for children as they grow into adults and providing support to families with disabled children. Advances in medicine and technology have meant that each year many children survive who would not otherwise have done so. Some of these children will require lifelong healthcare, social and educational support to be able to enjoy a reasonable quality of life. Yet in the UK, current support for disabled people and their families is uneven at best and, without adequate support, disabled children are unlikely to reach their full potential.
- 9.46 In the UK the law currently prohibits active measures to end the life of the newborn, a position which, as we have said, the Working Party endorses. Clinical guidelines impose very strict conditions limiting when treatment for life support can be withdrawn from a baby. There is also legislation to protect disabled people from discrimination (see Chapter 7). In other words, UK practice is to save life where possible and to protect the quality of that life. It is our view that consistency in this regard is essential. Adequate support for the lives of those people whose existence we endorse through decisions taken at or shortly after birth must be provided. By default, the current inadequacies of provision have a negative impact on the quality of life, not only for the child, but also their family. In this context we note the importance of specialist short- and long-term foster care for seriously disabled children.¹⁷ **We endorse Standard 8 of the National Service Framework for Children which states a requirement for families to be provided with a range of appropriate family support services that are flexible and responsive to their needs, and recommend that this should apply to all national governments and assemblies responsible for the different countries of the UK.¹⁸ In this regard we urge the UK Departments of Health; Education and Skills; and Work and Pensions to accept further responsibility for supporting families who care for disabled children and adults by providing more resources to ensure that adequate and effective services are provided uniformly across the UK. We also ask the Departments of Health; and Education and Skills to provide the necessary resources to monitor this provision of care.**

Monitoring and research

- 9.47 It is the view of the Working Party that measures are required to help reduce the uncertainty currently associated with making decisions during pregnancy on the critical care of a fetus or, after birth, about a baby. We identify two broad areas for action: improved processes of communication and the need for more data on outcomes.
- 9.48 We gained valuable information and insight from experienced clinical teams working in this field, from parents who shared their experiences of critical care decisions made for their baby (see Appendix 1), from the research data that are available (see Chapter 5) and from our wider consultation (see Appendix 2). However, while first-hand experiences convey some sense of many of the issues, they cannot be seen as definitive and may miss some of the complexity of how different parties view those issues. To help to identify variations in practice, experience and views, further research is required. **The Working Party therefore recommends to the RCOG, the RCPCH, the RCN, the NNA and the RCM that objective, systematic (obser-**

¹⁷ The Department of Health announced a review on the long-term sustainability of children's hospices on 29 May 2006.

¹⁸ See Disabled Child Standard, *National Service Framework for Children, Young People and Maternity Services*, available at: <http://www.dh.gov.uk/assetRoot/04/09/05/56/04090556.pdf>, accessed on: 17 July 2006.

vational and interview) data, rigorously analysed, are needed on how the different parties interact when making decisions to resuscitate babies who are critically ill or born at the borderline of viability, and also decisions to withdraw intensive care. This information will further understanding, provide an evidence base for identifying and applying changes to guidelines for practice, and assist with the more effective resolution of differences of opinion (paragraph 6.26). There is also little evidence available on how prior experience influences either clinical teams or parents, in terms of wider personal, familial, social and cultural factors (paragraph 3.21). **Sociological research is needed to identify these factors and the extent to which they carry weight as individuals interact during the decision-making process.**

9.49 Neonatal critical care decisions are particularly difficult because of the lack of information from long-term follow up on which to base predictions of future health outcomes. It is crucial that accurate and up-to-date evidence from research is available to doctors and parents about the risks to and likely outcomes for babies in whom a birth abnormality or genetic disorder has been recognised antenatally or in the newborn period, as well as for extremely premature babies. Follow up is needed not only for groups of children diagnosed with health difficulties before or around the time of birth, but also for children who have minor symptoms at birth but are at potential risk of late-onset problems.¹⁹ **Our view is that data linkage with longer-term events in later stages of a child's life, through adolescence to adulthood, captured through NHS health records and educational records, will provide crucial information on outcomes. Although the necessary electronic NHS systems are not yet in place, it is timely to consider the health-related questions that should be posed and corresponding requirements for data collection (see paragraphs 6.45–6.50).** We recommend that proposals for studies based solely on data linkage, that do not require contact with patients or their families, should be referred to the Department of Health Patient Information Advisory Group to request access to the relevant patient information, on grounds that it would be strongly in the public interest to determine outcomes from critical care decisions.²⁰

9.50 In addition to the follow up of babies for whom critical care decisions had to be made at the fetal or neonatal stage, our view is that, provided the subject is introduced sensitively and appropriately and there is parental consent, useful information can be gained from autopsy examinations for fetuses and babies who do not survive. Autopsy data may provide some insights into the cause of death and help parents in planning future pregnancies. Furthermore, if doctors can gain a better understanding of the causes underlying clinical conditions, other parents can be given more accurate information when making decisions, and research efforts can be directed towards obtaining more precise diagnoses. **Therefore the Working Party encourages doctors to recommend and parents to consider autopsy in order to add to knowledge about causes of death (see paragraph 6.51).**

Information, education and training

9.51 Good decision making in critical care depends on the quality and comprehensibility of the information available to parents and how that information is conveyed by healthcare professionals. **Parents need timely provision of accessible information on the nature of potential disability and long-term consequences of decisions made in fetal and neonatal med-**

¹⁹ The Working Party notes that a similar need for long-term follow up of children has been identified in the USA, and in other areas where there is a potential but unanticipated risk of late-onset problems, for example arising from acquired brain injury.

²⁰ See <http://www.advisorybodies.doh.gov.uk/piag/>, accessed on: 26 May 2006.

²¹ The NSF for Children recommends that women should make informed choices and plan their care in partnership with professionals and that a woman should have easy access to information and support throughout her pregnancy. The relevant NSF care pathway is at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 17 July 2006.

icine. We propose that, where appropriate, this material should be provided as part of the individually based pathway of care for a pregnant woman.²¹ For example, pregnant women for whom an extremely premature birth is imminent should, where practicable, be given written information on prematurity, explaining the risks and the procedures that will occur.²² **The information needs to be available in different languages and formats to meet the needs of different individuals, as specified in the Standards of the National Service Framework for Children.²³ It should include both national and local statistics and be updated regularly. We emphasise that written information must be accompanied by face to face discussion and explanation with the expectant mother and her partner or others who are there to support her (if she wishes).**

- 9.52 **We recommend that standards for the provision of such information need to be developed and implemented by the relevant organisations. We propose that such organisations (for example, the RCOG, RCPCH, BAPM, RCN, NNA and RCM) should liaise with groups that advocate for parents (for example, the National Childbirth Trust (NCT), BLISS – The premature baby charity and the Stillbirth and Neonatal Death Charity (SANDS)) and that the Healthcare Commission should monitor delivery of this information to measurable standards. We recommend that any discussions about the provision of information would benefit from the involvement of families and others who have direct experience of continuing specialist care at home after leaving hospital or of what disability can mean for older children and their families.** Account should be taken of the NICE standards for information-giving during pregnancy and the neonatal period and the RCPCH standards required for professional competency in neonatal medicine, which cover communication skills.²⁴
- 9.53 **As part of this proposed collaboration on standards for information giving, we recommend that the relevant organisations should develop, and evaluate the value and feasibility of, making written or audiovisual guides available for local use by fetal medicine and neonatal intensive care units. These guides would promote continuing education in fetal and neonatal medicine by setting out how healthcare professionals should approach critical care decision making.** We note that healthcare professionals are likely to need specific training to help them understand the perspectives of parents faced with critical care decisions and to communicate effectively with them. This training could also help doctors and nurses reconcile decisions that are different from the choices they would have made for themselves.
- 9.54 Misunderstandings about the role of the criminal law in relation to withholding and withdrawing treatment are not uncommon. Similarly, healthcare professionals are not always well acquainted with broader ethical debates outside the general guidance offered by their professional organisations. **We therefore recommend that the RCOG, RCPCH, RCM, RCN and the NNA should encourage medical and nursing schools to develop undergraduate and postgraduate educational programmes in the law and ethics relating to fetal and neonatal medicine, as appropriate.**

²² We acknowledge that a woman who is about to give birth will not necessarily be in a state of mind to read or digest written information. Nevertheless, it may be valuable to her later; and if a partner, family member or friend is with her, they may find it helpful.

²³ Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006.

²⁴ National Collaborating Centre for Women's and Children's Health, Commissioned by the National Institute for Clinical Excellence (2003) *Antenatal Care: Routine care for the healthy pregnant woman* (London: RCOG Press); National Institute for Clinical Excellence (2006) *Routine Post-natal Care of Women and their Babies*, available at: <http://www.nice.org.uk/page.aspx?o=CG37>, accessed on: 28 Sept 2006; Royal College of Paediatrics and Child Health Specialist Advisory Committee for Neonatal Medicine (2001) *Competency Framework for Sub-Specialty Training in Neonatal Medicine* (London: RCPCH).