Chapter 5

Dilemmas in current practice: babies born at the borderline of viability
Dilemmas in current practice: babies born at the borderline of viability

Introduction

5.1 We use the term ‘borderline of viability’ to describe the time of birth of extremely premature babies who are born alive at or before the gestational age of 25 weeks and six days.¹ This limit has fallen by approximately one week every decade over the past 40 years, and may be attributed at least in part to advances in technology and care. Babies are born at this early stage of gestation because of spontaneous labour or because of early delivery to safeguard the health of the baby or mother or both. At these stages of gestation, the prospects of healthy survival are reduced and for this reason critical care decisions after birth may need to be taken. Multidisciplinary discussions between neonatal and maternity staff, including obstetricians and midwives, are of paramount importance. Plans must be made about a series of steps in clinical management that will need to be discussed with the mother and, where possible, her partner, so that the best decisions can be made for caring for her and the baby.

5.2 Where labour at borderline viability is likely, several practical decisions must be taken about the best way to manage care. For example, if a pregnant woman is admitted to a district general hospital, should she be transferred to a hospital with a specialist fetal medicine or a (level 3) neonatal unit?² ³ Is it safe to do so for her and the baby or would it be too far from her home? Is there a local Neonatal or Neonatal Network⁴ with guidelines that should be followed? A decision will also need to be made about whether a Caesarean section should be performed, bearing in mind that at this stage of pregnancy this surgical procedure is a serious and hazardous intervention for the woman that may affect her future reproductive capacity.⁵ If there is little prospect that treatment can improve the health of the baby, a decision may also need to be made about whether palliative rather than intensive care should be provided after birth (paragraphs 6.18–6.22). While these are primarily obstetric decisions,

¹ Measurements are from the first day of the pregnant woman’s last menstrual period[0]. By convention, the number of weeks of gestation refers to the period from the first to the last day of that week. For example ‘at 23 weeks’ means from 23 weeks to 23 weeks, six days of gestation (161–167 days of gestation).

² In a level 3 neonatal unit, staff have exclusive responsibility for neonatal care and have no other paediatric responsibilities. Since 2003, Department of Health policy has been that babies with complex care needs or requiring long periods of respiratory support should be cared for initially in a level 3 unit, especially if born at 27 weeks of gestation or less. See Department of Health (2003) Report of the Neonatal Intensive Care Services Review Group, available at: http://www.dh.gov.uk/assetRoot/04/01/87/44/04018744.pdf, accessed on: 15 June 2006.


⁴ It is the policy of the Department of Health to provide all neonatal care in England within agreed managed clinical networks comprising a number of hospitals with differing types of neonatal unit (Department of Health (2003) Report of the Neonatal Intensive Care Services Review Group, available at: http://www.dh.gov.uk/assetRoot/04/01/87/44/04018744.pdf, accessed on: 15 June 2006). This strategy is encouraged by BAPM (British Association of Perinatal Medicine (2001) Standards for Hospitals Providing Neonatal Intensive and High Dependency Care, 2nd Edition, available at: http://www.bapm.org/media/documents/publications/hosp_standards.pdf, accessed on: 5 Sep 2006). There are 24 such networks in England, and these are called either Neonatal Networks or Perinatal Networks. (See NHS Neonatal Networks What is a Neonatal Network?, available at: http://www.nationalneonatal.org.uk/Healthcare+Professionals/About+the+Networks/, accessed on: 18 Aug 2006.) The aim of these networks is to ensure that groups of hospitals and units work together to offer a range of levels of care and improve the services they offer. The networks are intended to facilitate the concentration of skills and expertise required within an area, and encourage transfers to local units in order to offer high-quality and appropriate neonatal care close to the mother’s home.

⁵ A classical Caesarean section would be required, which involves opening the abdomen and the upper part of the uterus, unlike the operation which is usually performed at or near term in which only the lower part of the uterus is opened (lower segment Caesarean section). The uterus is more likely to rupture in a future labour if there is a scar from a previous classical Caesarean than from a lower segment Caesarean section.
they can only be made sensibly in the context of plans determined jointly between all professional groups and the parents. The clinical staff at the neonatal unit will need to determine whether there are sufficient expertise and resources available to provide optimal care of the baby. They should also ascertain whether the parents want the baby’s life to be supported by active intervention, and obtain their view on what should be done if the baby is in unexpectedly good or poor condition. When labour occurs spontaneously, there may be very little opportunity to plan ahead.

5.3 We begin by explaining how survival rates for babies at the borderline of viability have improved, and describe current clinical practice in the UK. We then provide some examples to illustrate the kinds of dilemma that parents and health professionals may encounter when making decisions in these difficult cases. Each example is examined from ethical, social and legal perspectives, followed by a consideration of economic issues.6

The clinical perspective

5.4 There has been longstanding professional disagreement about the range of gestational ages or birthweights at which providing babies with all possible clinical interventions is justified. At borderline viability there is a 50% or less chance of survival. The estimation of fetal gestational age has become more accurate as ultrasound technology and pregnancy testing have improved. Based on the date of the woman’s last menstrual period, the estimates are generally confirmed by ultrasound imaging. This method, generally considered to be more reliable than menstrual dating, is accurate to within five days in over 95% of cases when carried out in the first trimester of pregnancy.7 Because fetal weight cannot be measured accurately before birth, neonatologists in the UK tend to determine borderline viability by gestational criteria rather than by birthweight (the criterion being the weight at which there is a 50% or less chance of survival). However, older reports of clinical management are frequently based on birthweight because of past inaccuracies in the assessment of gestational age, and clinicians may refer to both birthweight- and gestation-based studies. The approximate equivalent of extreme prematurity is a birthweight of less than 1,000 g.

5.5 At present, survival at 22 weeks of gestation is very rare and, below this stage, almost unrecorded; these babies are sometimes termed ‘pre-viable’ for this reason. During the period of borderline viability (before 26 weeks), relatively few babies are born and most do not survive. In the past, their births would have been classified as miscarriages. Since the beginning of the 1980s, the proportion of babies that are born with an extremely low birthweight8 (most usually premature) has increased, with the percentage doubling between 1982 and 1996.9 In England, approximately 1,600 out of 584,000 estimated deliveries per year (i.e. 0.28%) are before 25 weeks, six days of gestation (see Box 5.1).10

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6 We use examples that are representative of what occurs in hospital. They are not based on clinical cases. In the discussion of each example, issues are highlighted, some of which were drawn to the attention of members of the Working Party during fact-finding meetings. We acknowledge that the choice of the issues that we discuss after each example may influence how the examples themselves are perceived by different readers, depending upon the reader’s own worldview.


8 See Box 3.1 for definitions. Extremely low birthweight babies weigh less than 1,000 g. Gestational age for live births has not been recorded separately in England. Birthweight, however, has been recorded over several decades in England and Wales and therefore is used to consider trends. See Macfarlane A and Mugford M (2000) Birth Counts: Statistics of pregnancy and childbirth, 2nd Edition, Volume 1 (London: The Stationery Office), pp55–6. The total number of deliveries (live births and stillbirths) by gestation is now recorded and the most recent figures available are included in Box 5.1.


10 National Statistics (2006) NHS Maternity Statistics, England: 2004–05, Table 21. It is not possible to give precise figures of babies born alive at these gestations because the standard data collected do not distinguish live and stillbirths. However, data on stillbirths reveal that, during 2003 in England and Wales, 3,585 babies were stillborn at 24 weeks[0] of gestation onwards until full term.
Critical care decisions in fetal and neonatal medicine

CHAPTER 5

DILEMMAS IN CURRENT PRACTICE: BABIES BORN AT THE BORDERLINE OF VIABILITY

Box 5.1: Birth statistics*

In 2004–5 in NHS hospitals in England, approximately 13% of all deliveries were premature (before 37 weeks, six days of pregnancy) (the data include both live and stillbirths). The total estimated number of deliveries was approximately 584,000.

Total deliveries by weeks of gestation in England 2004–5

<table>
<thead>
<tr>
<th>Weeks of Gestation</th>
<th>Deliveries</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20 weeks</td>
<td>40</td>
<td>&lt; 0.01%</td>
</tr>
<tr>
<td>20 weeks</td>
<td>50</td>
<td>&lt; 0.01%</td>
</tr>
<tr>
<td>21 weeks</td>
<td>80</td>
<td>0.01%</td>
</tr>
<tr>
<td>22 weeks</td>
<td>100</td>
<td>0.02%</td>
</tr>
<tr>
<td>23 weeks</td>
<td>240</td>
<td>0.04%</td>
</tr>
<tr>
<td>24 weeks</td>
<td>600</td>
<td>0.1%</td>
</tr>
<tr>
<td>25 weeks</td>
<td>500</td>
<td>0.1%</td>
</tr>
<tr>
<td>26 weeks</td>
<td>700</td>
<td>0.1%</td>
</tr>
<tr>
<td>27 weeks</td>
<td>800</td>
<td>0.1%</td>
</tr>
<tr>
<td>28–31 weeks</td>
<td>5,000</td>
<td>0.9%</td>
</tr>
<tr>
<td>32–36 weeks</td>
<td>35,100</td>
<td>6%</td>
</tr>
<tr>
<td>37–41 weeks</td>
<td>515,000</td>
<td>88%</td>
</tr>
<tr>
<td>42 weeks or over</td>
<td>26,050</td>
<td>4.5%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>584,260</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

(The number of babies delivered at the ‘borderline of viability’, or before 25 weeks, six days of gestation, was approximately 1,610 (0.3%).)

Deliveries by gestational age (%) for singletons and twins in England

Of these, 27% (957) were stillbirths delivered between 24 weeks and 27 weeks, six days of gestation (National Statistics (2005) Mortality Statistics: Childhood, infant and perinatal 2003 Series DH3 No. 36 (London: Office for National Statistics), Table 13). For Scotland in 2003, there were 260 stillbirths of singletons of which 55 occurred between 24–27 weeks of gestation (21%). At these gestational ages, 32% of all deliveries of singletons (total 174) were stillborn (NHS National Services Scotland (2003) Scottish Perinatal and Infant Mortality and Morbidity Report (NHS Scotland: Edinburgh), Table 22b).
5.6 Borderline viability has always been associated with the presence of disabilities in a proportion of survivors. In 1981, a review of published literature concluded that survival for babies weighing less than 1,500 g at birth (approximating to 30 weeks of gestation) had improved over time, particularly since the 1960s, whereas the proportion of babies born alive who survived with ‘handicap’ (their term) had remained stable. Since this important study, survival rates at lower gestations have continued to improve and have played a part in the legal definition of stillbirth being changed from 28 weeks of gestation and above, to 24 weeks and above in 1992. Criticism is often made of the practice of providing intensive care for babies born at the borderline of viability. However, evaluations have shown that for the relatively few babies at the borderline of viability who survive, by the age of six years, most have moderate, mild or no disabilities, rather than disabilities which are categorised as severe (see paragraph 5.8 and Table 5.1). The continued assessment of outcomes for this group is critical and was the main reason for initiating the EPICure study, to which we now turn.

The EPICure study

5.7 Extreme prematurity continues to pose serious dilemmas for parents and healthcare professionals as several disabling conditions are known to occur with much greater frequency among survivors than is the case for babies born at full term (Table 5.1 and Box 5.2). In 1995, the EPICure study was undertaken to address the paucity of data on survival and long-term outcome for extremely premature babies. The study identified all births between 20 and 25 weeks, six days of gestation in the UK and the Republic of Ireland during a ten month period in 1995. Of the 4,000 births recorded, 1,185 babies showed signs of life at birth. The prevalence of live birth at 23 weeks of gestation was 39%; at 24 weeks it was 60%; and at 25 weeks, 67%. The study has since followed the progress of the 308 babies who survived until discharge from hospital for babies born at the threshold of viability "Pediatrics" 106: 659–71.


12 Below 24 weeks of gestation the loss of a pregnancy is classified as a miscarriage.


discharge from hospital, at two and a half, and approximately six years of age, and will soon report at ten years. It represents the outcome for babies born in all types of hospital across the entire geographic area, and thus broadly reflects clinical practice in 1995. The care of these babies ranged from the provision of full care to palliative care only. A second EPI Cure study will collect information on babies born in England during 2006 before 26 weeks, six days of gestation (thus including one more week than in the original study).

5.8 The outcomes for those babies who showed signs of life at birth are shown in Table 5.1. As the data are based on the performance of the children against their peers, rather than their individual quality of life, they give the most pessimistic view of outcome. Moreover, they include any disabling condition, of which many are categorised as ‘mild’ disabilities that do not interfere significantly with everyday life, such as the need for spectacles or having moderately low IQ scores. The table indicates the numbers and percentages of babies born alive, admitted for intensive care, and with disability at six years. At 23 weeks of gestation, for example, a total of 241 babies were born who showed signs of life, of whom just under half died in the delivery room and were not admitted for continuing care. Of those admitted to intensive care, 26 survived to discharge from hospital. Only 3% survived without any disabilities classified as severe or moderate. For the entire cohort of surviving children (born between 22 and 25 weeks, six days) who were assessed at approximately six years of age, the rates of severe, moderate and mild disability were 22%, 24% and 34% respectively. Disabling cerebral palsy was present in 30 children (12%). These high rates of disability are a cause for concern.

Table 5.1: Summary of outcomes up to six years of age among children born alive at different gestational ages in the 1995 EPICure study.

<table>
<thead>
<tr>
<th>Weeks of gestation at birth</th>
<th>Number (percentage of total)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome</strong></td>
<td>22 weeks</td>
</tr>
<tr>
<td>Showed signs of life at birth</td>
<td>138 (100)</td>
</tr>
<tr>
<td>Admitted to intensive care</td>
<td>22 (16)</td>
</tr>
<tr>
<td>Survived to discharge from hospital</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Died by the age of 6 years</td>
<td>136 (99)</td>
</tr>
<tr>
<td>Lost to follow up at 6 years of age</td>
<td>0</td>
</tr>
<tr>
<td>Remaining in study at 6 years of age: Totals</td>
<td>2 (1)</td>
</tr>
<tr>
<td>With severe disability</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td>With moderate disability</td>
<td>0</td>
</tr>
<tr>
<td>With mild disability</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td>With no impairment</td>
<td>0</td>
</tr>
</tbody>
</table>

* Defined as an IQ score more than three standard deviations below the mean.
† Defined as an IQ score between two and three standard deviations below the mean.

16 Follow up studies inevitably reflect practice at the time that data are collected and would not include the effects of recent changes, such as improvements in neonatal medicine or the reorganisation of hospital systems providing neonatal care that has occurred since 2003.


19 The percentages are calculated from the total number of babies born alive at each gestational age.
Box 5.2: The main categories of disability in premature babies*

- **Cerebral palsy** – particularly affects the lower limbs (diplegia), and may result from injury to the brain. Some children have severe disability with spasticity affecting all four limbs whereas others have very mild impairments which may only slightly restrict activity. Up to a quarter of extremely premature survivors may have some form of cerebral palsy but only half of these children have disability that restricts activity significantly.

- **Other motor problems** – a proportion of children without cerebral palsy may have motor difficulties that cause them to appear relatively ‘clumsy’ compared to their classmates at school; some will need help from an occupational or physiotherapist.

- **Visual impairment** – blindness may result from a condition called ‘retinopathy of prematurity’ where abnormal vessel development occurs in the back of the eye of the extremely premature baby; fortunately this outcome is rare (< 5%) and modern laser treatment can help in some cases. Less severe visual problems, such as squints and need for spectacles, are relatively common, and some are related to mild retinopathy.

- **Hearing impairment** – a small number of preterm children develop deafness and some require hearing aids.

- **Learning difficulties** – following very preterm birth, about 10–15% of children have major neurodevelopmental problems, and a further 30–40% develop less severe motor, neurodevelopmental or learning problems by school age.21 The cause of the major neurodevelopmental problems is thought to be damage to the white matter in the brain during the perinatal period. The cause of the less severe later problems is unclear but may be associated with reduced postnatal growth, particularly of the head.22 Children with learning difficulties require individual assessment, and support in the classroom.

- **Behavioural problems** – attention deficit disorder is found more frequently in children who have been born prematurely; individual assessment is needed but effective developmental strategies and medical treatments are available.

- **Respiratory problems** – lung development after neonatal intensive care may be compromised, particularly in extremely preterm babies. Chronic respiratory symptoms of cough and wheeze may require continuing treatment in childhood for some children.

- **Growth problems** – children born at borderline viability are often small throughout childhood but many catch up during the pubertal growth spurt.

- **Disability** – reports of outcomes following premature birth generally combine many outcomes into categories of severe, moderate, mild or no disability. Although these categories provide a convenient shorthand for describing outcome, severe disability is in fact made up of different combinations of the very different outcomes described above.


5.9 Since 1995, survival at the borderline of viability to discharge from hospital has continued to improve, primarily in children born after 24 weeks of gestation or more; for example data for the Trent region of the UK are shown in Figure 5.1. There are no current data from the Trent survey available to indicate whether the incidence of disability has altered, although some beneficial changes have been reported that are thought to have arisen through improved use of antenatal steroid therapy and surfactant treatment at delivery. There has also been a reduction in the use of ventilation and postnatal steroid treatments, both now thought to contribute to health problems. The second EPICure study (see paragraph 5.7) aims to find out if outcomes for premature babies in the UK have changed in the past decade.23

5.10 There is evidence from other countries that the survival rate at 23 weeks of gestation has improved since the 1995 EPICure study, although caution is needed when comparing studies involving different populations. A national study of all births recorded in Norway from 1999 to 2000 showed that survival to discharge from hospital was 16% for babies born at 23 weeks and 44% at 24 weeks of gestation.24 Both figures are higher than the rates recorded in the
EPICure study and similar to data from the Trent neonatal survey. A Swedish study of births between 1992 and 1998 showed even higher rates of survival: 43% at 23 weeks and 63% survival at 24 weeks. In this study, fetal monitoring was carried out and, if necessary, Caesarean section, at 23 weeks onwards. All infants with any signs of life were actively resuscitated and brought to the neonatal intensive care unit. Decisions to withdraw respiratory care were avoided during the first days of life and subsequent withdrawal of intensive care was rare. The Swedish data are important as they show that, even with a policy of resuscitating every baby and almost never withdrawing life support, the majority of babies at 23 weeks still died. Thirty per cent of the babies born at 23 weeks died before seven days, 20% died between seven and 28 days of age and 10% died after 28 days. Data from an Australian study suggest that the frequency of neurosensory problems in extremely low birthweight children born in 1991–1992 remains higher than in normal birthweight children, but has dropped when compared with data from earlier decades. Data from these studies are too limited for the Working Party to be able to conclude that disability in children surviving birth at the borderline of viability has improved. The new EPICure study will show whether the rates of survival and disabling conditions have changed nationally over the 11 years since the first study.

In summary, the Working Party concludes that the 1995 EPICure data on the long-term developmental outcomes of babies born at the borderline of viability remain the best available for advising parents in the UK on likely outcomes in terms of disabling conditions. This is because the data were collected in a systematic way, are based on the UK and Irish population, and, by nature, require a number of years

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to collect. By contrast, if parents are interested primarily in knowing the most up-to-date rates of survival, the survival rates reported from the EPICure study are consistently lower than those achieved now and are therefore less helpful for providing advice to parents.

5.11 At present, studies that assess the impact of outcomes on the child and their family and explore the relationship of outcome to perinatal management are funded through research grants. The Working Party concludes that data from follow up should be pooled by clinical services in all hospitals, using standardised definitions, so that statistics can be collated year on year. Developing systems for continuous collation of data would allow routine monitoring of practice and outcome in this important area. We discuss the question of follow up and research studies further in Chapter 6.

UK practice for resuscitation of babies at the borderline of viability

5.12 Where delivery at borderline viability is anticipated and time allows, most neonatologists or paediatricians will discuss whether to institute resuscitation with the parents before delivery. Consideration will also be given to the baby’s need for relief of pain and discomfort (see paragraphs 6.14–6.17). The doctors will try to ascertain whether parents would want resuscitation or, if there is little chance of survival, they would prefer the baby to be given palliative care alone, allowing him or her to die without the stress and pain of attempted resuscitation and intensive care. The decision to provide only palliative care will entail a careful assessment of the baby immediately on delivery to confirm that the estimation of gestational age is correct. The condition of the baby will then be evaluated, followed by medical and midwifery support for the baby and mother without life-prolonging medical intervention. Maximising the baby’s quality of life through relief from pain and stress is an important part of palliative care (see paragraphs 6.18–6.22). This series of steps is supported by guidance from professional bodies (see Appendix 9).

5.13 Up to 22 weeks, six days of gestation, survival to discharge from intensive care is widely regarded as highly unlikely and resuscitation is usually rejected as futile, even if a mother were to request it. However, a very small number of neonatologists in the UK initiate life support for babies who are born at 22 weeks. The number of survivors who live for several years remains very low and reports of follow up are limited. During its deliberations, the Working Party was not made aware of any substantive data to suggest that babies have survived following birth at less than 22 weeks of gestational age. While we are aware of therapeutic developments being investigated that could, if successful, be applied to extend viability, our understanding is that this would not be at any point in the near future. Some doctors consider the institution of full intensive care below 22 completed weeks as treatment, whereas others consider it to be experimental. While experimental studies are important to advance practice, it is our view that attempts to prolong life following birth before 22 weeks of gestation should be carried out only as part of a research study that has previously


32 By the term ‘futile’, we mean an intervention or treatment that would delay death but is judged to improve neither life’s quality nor potential.

33 For example, in the areas of fetal imaging and monitoring, detection and delay of premature labour, and ventilatory support.
been assessed and approved by a research ethics committee. For such a study, the parents would need to consent in advance to the resuscitation and active treatment of their baby (see also recommendation in paragraph 9.19). We say more about clinical trials in Appendix 6.

5.14 At gestational ages of 22–25 weeks, every effort is made to anticipate delivery once the signs are that a premature birth is likely. These plans include the presence of experienced members of the obstetric and neonatal teams at the birth to assist with the assessment of the baby and to support parents and staff in carrying out life support or palliative care.34 However this level of planning may not always be possible if, for example, the birth is unexpected. The parents’ wishes may influence the level of care that doctors will advise for a baby at the borderline of viability to an extent that they would not in a baby of later gestational age. Clinicians report that mothers have given different reasons for not wanting life support to be provided. Women may have stated emphatically that they do not want their baby to be subjected to prolonged intensive care, or feel that they could not cope with a disabled child, or believe that they could easily get pregnant again. In such cases, the neonatologist may be more likely to opt for palliative care for a baby born in poor condition. If, on the other hand, a mother may not have another chance to have a pregnancy (for example after extensive fertility treatment), and she is willing to accept any outcome if the child survives, the doctor is likely to use all appropriate therapy to support the baby, even if the chances of survival without some level of disability are very low.

5.15 Current evidence does not support the institution of active care for babies born at 22 weeks of gestation, as the chances of survival are minimal and a very high proportion of survivors are likely to be seriously disabled, although in studies the numbers of survivors have been very small. It is rare for doctors to undertake active intervention, although they will carry out a careful postnatal assessment to verify the gestational age.

5.16 It is at 23 weeks of gestation (the period from 23 weeks to 23 weeks, six days) where there is greatest uncertainty about the outcome for an individual baby and where the decision on whether treatment is in his or her best interests is most difficult to make. Assessing the condition of the baby in the first five minutes does not help in identifying those who will be unable to survive or those who will survive without disability.35 Many doctors would only institute active care at this gestational stage if the parents were in clear agreement that they should do so. Variation in clinical practice is probably greatest at this stage of gestation and will, accordingly, affect figures for survival and almost certainly rates of disability.

5.17 At 24 weeks, the chances of survival improve, although there remains a high chance of some level of disability. Increasingly, it is normal practice for a baby to be offered full intensive care and support from birth, and admitted to a neonatal intensive care unit. Many doctors consider this practice appropriate. However, they would also listen carefully to the wishes of parents and give their views due weight when making decisions immediately after birth if the baby is in poor condition, or not responding to resuscitative measures.


35 Attempts to find predictors of poor outcomes have been unsuccessful. For example a recent study examined the predictive value of the APGAR score in 126 infants weighing less than 1,000 g who were born alive and resuscitated but found it was not a good predictor of outcome. Andrews B, Lagatta J, Calderelli L et al. (2006) Uninformed Non-Consent in the Delivery Room? Ethical implications of poor predictive value of burdensome outcome in the first minutes of life, presented at the Pediatric Academic Societies Annual Meeting, San Francisco, 2 May 2006. Guidance in the USA states that “Apgar score at 1 minute and 5 minutes is not appropriate for predicting long-term outcome”, American Academy of Pediatrics, Committee on Fetus and Newborn, American College of Obstetricians and Gynecologists and Committee on Obstetric Practice (2006) Policy Statement: The Apgar score Pediatrics 117: 1444–7.
5.18 From 26 weeks of gestation and in recent years, from 25 weeks and above, the actions of the neonatologist would not normally be influenced by the parents’ wishes or experiences in the way described above. The outlook for babies at this gestation is considered to be sufficiently good, in terms of survival without severe disability, that resuscitation would be judged to be in the baby’s best interests without qualification, as would also be the case at later gestations.

5.19 Whatever the gestational age at delivery, it is the responsibility of the senior neonatologist to arrive at, and explain, the best possible assessment of what can be achieved with life support in the delivery room. The discussion includes possible outcomes and courses of action and involves the various members of the perinatal team, who each bring a different expertise and perspective, as well as the pregnant woman and her partner if she chooses. If there is doubt about the outcome or the correct action, or if the discussion with the parents has been inconclusive, practice in the UK is to provide support; this is in keeping with professional guidelines. Support entails providing active resuscitation, transfer to a neonatal intensive care unit, and reassessment at a later stage. A baby may be in intensive care for varying periods depending upon his or her needs. It is extremely difficult, at around 23 weeks of gestation, for the neonatologist to identify which course of action is in an individual baby’s best interests. Invasive life support may do harm because intubation, ventilation and insertion of catheters into blood vessels may prolong stress, pain and discomfort before inevitable death in the majority of babies, compared with a relatively rapid and peaceful death if no life support is given. However, active life support may increase the chances of healthy survival (albeit with a high chance of some disability) for a minority, compared with a more cautious approach.

5.20 Practice elsewhere differs from country to country. In the 1980s and 1990s, the approaches followed in some parts of the USA and the Netherlands appeared to be at opposite ends of a spectrum. A recent study showed that in the mid-1980s, 95% of babies born at 23–26 weeks of gestation in an area of New Jersey, USA, received mechanical ventilation in contrast to only 64% in the Netherlands (see also Box 8.1). The proportion of babies that survived to the age of two in New Jersey was found to be double that in the Netherlands, and the proportion that had disabling cerebral palsy was five times greater in the babies from New Jersey. Among those who died, 45% of the Dutch babies had not received any ventilation compared with only 10% of the New Jersey babies. There have been several other studies that show that doctors in different countries approach critical care decision making in neonatal medicine in different ways.

5.21 The Working Party made visits to France and the Netherlands in early 2006, to hear first-hand about current practices in neonatal and fetal medicine. These two countries were chosen because the general approach differs from that followed in the UK. In the Netherlands active ending of life is more widely accepted and, for adults, is supported by legislation. In France,
clinical practice has been characterised as paternalistic, with one study from the 1990s finding that French hospitals typically would "sound out" parent's views and "take them into account" rather than directly including parents in decisions involving withholding or withdrawing intensive care from a baby. The Working Party discussed policy, practices and attitudes to resuscitation, as well as the active ending of life with clinicians, ethicists and lawyers from both countries.

5.22 Decisions to withhold or withdraw life-sustaining treatment in the UK involve parents more often than is the case in other European countries although practices are changing. In France, the more traditional practice of allowing doctors to decide is beginning to give way and increasingly, more emphasis is being placed on understanding the parents' wishes. Twenty years ago, resuscitation of very premature babies was routine practice, followed by re-evaluation once a firmer prognosis had been established. For babies with a poor prognosis, ventilation would be withdrawn or an injection given deliberately to end life. However, an increasing number of French neonatologists now have reservations about following this approach, and believe that common standards for practice should be agreed for use throughout the country. Recently, the Fédération Nationale des Pédiatres Néonatologistes established a review to explore these issues but the outcome is unlikely to be known for some time.

5.23 In the Netherlands, a consensus had been reached by 2003 that obstetricians and neonatologists at all Dutch perinatal centres should not normally resuscitate and treat extremely premature babies born before 25 weeks of gestation, because of poor outcomes (see Box 8.1). Instead, these babies are offered palliative care with their parents present, and allowed to die in the delivery room, instead of being admitted to the neonatal intensive care unit. Exceptions might, however, be made if the parents were strongly in favour of resuscitation or if the baby appeared to be particularly healthy. These criteria are currently being reviewed. There is further discussion on the practice of resuscitation in Chapter 8.

Some examples

5.24 We now describe several hypothetical situations that help to illustrate the complex reality of decision making for babies at the borderline of viability in the UK. In the first case, a decision has been taken not to prolong life yet the baby unexpectedly survives. The circumstances of the second case involve deciding whether or not to take steps to prolong life by resuscitating the baby. In the third case, the baby's parents disagree about what is best for him.

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44 Ibid.
46 Personal communication to the Working Party.
49 See footnote 6.
Case 3: Ahmed – decision making in the delivery room

Ahmed

A 32-year-old mother of two healthy children was admitted to hospital after her waters broke at 23 weeks of gestation. A consultant neonatologist discussed the prognosis and options if delivery took place at 23 weeks. The doctor explained that most babies at this stage of gestation died and, if they survived, there was only a slim chance (3%, based on a UK study) that the baby would survive without moderate or severe disabilities. She added that the clinical team would respect the parents’ wishes but that they did not normally resuscitate babies of this gestation. The situation was complicated because English was not the couple’s first language but the hospital was able to provide an interpreter. The mother and her husband decided that they did not want their baby to suffer and that they did not want resuscitation. After the delivery, the baby was wrapped and held by the mother and the baby, named Ahmed, made a few weak breathing movements and his heart rate was very slow (40 beats per minute).

After 60 minutes, the neonatologist was called to make an assessment of Ahmed who had gasping respirations and a moderately slow heart rate (100 beats per minute compared with the normal rate of more than 120 beats). The neonatologist began to consider whether resuscitation should be tried after all, or if Ahmed should be treated in other ways.

Best interests

5.25 We have seen in the case of Ahmed that the neonatologist, in consultation with the parents, made the decision not to resuscitate, guided by her own and their views about Ahmed’s best interests. We noted in Chapter 2 (paragraphs 2.24–2.25) that there are limitations to the usefulness of the concept of best interests. Some might say that here the principle has misled the parents and the medical professionals and precipitated a traumatic situation. However, there is always a significant degree of uncertainty involved in prognoses, and a judgement needs to be made. What this example underlines is that assessments of best interests are highly dependent on the particular circumstances of each case, which need to be conveyed in the decision-making process. Here, it was very important to make clear the uncertainties of prognosis.

Decision making

5.26 Although in Ahmed’s case there was agreement between parents and the clinical team about the initial treatment options before delivery, Ahmed was assessed after birth and found to be in a poor condition and thus, in keeping with the previous decision not to intervene, palliative care was given. Had he been in good health and breathing with a fast heart rate, the neonatologist might have reconsidered the initial decision. This illustrates that there is not a single moment or process of decision making, but rather a series of decisions. As circumstances change, prior decisions may need to be revisited.

5.27 Once Ahmed had survived for about an hour, there would be several potential options for clinical management. One option, after talking to his parents, would be for the neonatologist to continue the current level of support and not intervene. Ahmed’s clinical condition suggested that it was highly likely that he would die after a short while. His parents would need reassurance together with continuing emotional and practical support. Another option would be to treat Ahmed with a medicine to relieve the gasping respirations which seemed to cause him distress and were upsetting for his family to observe. A high dose of morphine, for example, would provide relief but might also quickly stop his breathing. If Ahmed should continue to breathe, a further option would be to provide non-invasive support for breathing, until it was clearer that his condition was continuing to deteriorate or he became more vigorous. Finally, the neonatologist might begin to think that, as Ahmed’s condition had improved and not deteriorated as anticipated, he may have much greater potential to survive without disability than originally thought. If so, the doctor might reverse the initial decision not to intervene and propose providing every assistance. This might cause him anxiety as it would not be clear in this situation whether the delay in intervention had also worsened the eventual outcome.

Cases 1 and 2 are in Chapter 3.
5.28 Normal practice in the UK would be for neonatologists to discuss these options openly with the parents, if this is possible. Where time permitted, doctors would review local and national guidelines and ideally talk the case through with colleagues. Some doctors might be inclined to overrule the expressed wishes of the parents and proceed with resuscitation.

5.29 Ahmed’s case is also complicated to some extent by the fact that his parents had a limited command of the English language and required an interpreter. This raises the question of whether the parents fully understood the severity of the disability and how it would probably affect their child before agreeing that resuscitation should not be attempted. They might not have been aware that sometimes a baby can survive against the odds. Interpreters are required not only during the first consultation or while signing a consent form (see Appendix 5), but should ideally be available throughout the decision-making process. Many neonatal units are able to access and provide language support, though advance notice is needed for the interpreter to come in person.51

Implications for the healthcare team

5.30 Cases such as that of Ahmed are likely to cause moral distress for members of the clinical care team involved, particularly when they believe their initial decision may have been mistaken.52 When making decisions about resuscitation, there may be no time to consult another doctor and even if the treating neonatologist has a conscientious objection to continuing the non-interventional management, it is unlikely to be possible for the case to be passed to another doctor. Neonatologists frequently have to make complex decisions on resuscitation. Research has shown that many doctors find such decision making and/or the carrying out of the actions decided upon to be difficult. They use different coping strategies, such as detachment from the situation, seeking (informal) support from colleagues, families and friends, and pursuing personal interests to maintain a balanced life.53 Within the clinical and nursing team, there can be disagreements between staff over decisions, or some individuals may have a different personal view to the lead doctor or parents, which can lead to conflicts and tensions.54 On a fact-finding visit to a neonatal unit, the Working Party learnt that healthcare teams deal in different ways with the emotional aspect of their professional practice. A health psychologist might be employed as part of the team; sometimes the arrangements might be less formal and colleagues would counsel each other. Many neonatal teams have regular formal meetings to discuss their management of cases in retrospect, which would be facilitated in unusual circumstances by a clinical ethics committee if one is available.

Legal issues

5.31 Ahmed’s case exemplifies the kind of circumstances that create anxieties about the law for doctors. Ahmed clearly made an effort to survive. Given his birth at 23 weeks of gestation, the decision not to resuscitate him would be unlikely to be legally questionable. However, because Ahmed struggled to breathe, the neonatologist had to re-assess what constituted appropriate care. Ahmed’s long-term prospects may well mean that prolonging his life was still not in his best interests. But the dilemma facing the doctor is very difficult to resolve. This is a case when clearer national guidelines might well be helpful, and support from a clinical ethics committee could be constructive.

51 A recent study found that 82% of units surveyed reported the possibility of parents having access to an interpreting service. BLISS – The Premature Baby Charity (2005) Special Care for Sick Babies – Choice or chance? (London: BLISS).
52 Work-related stress among senior doctors: review of research (June 2000). Produced by the BMA Health Policy and Economic Research Unit.
54 Ibid.
Case 4: Beth – parental influences on decision making

Beth

A 38-year-old woman was admitted to the labour ward in early labour at 22 weeks, six days of gestation. She had lost two pregnancies at 18 and 19 weeks, respectively, and was considered to have an ‘incompetent cervix’. At 14 weeks the obstetrician had placed a suture around her cervix to prevent it opening as her pregnancy progressed. She and her partner were advised that the chances of her baby surviving even with the best care were very low and that the staff had not seen a baby of this low gestation survive before. Even if the baby survived, the risk of moderate or severe disability was estimated to be more than 50%.

The parents were of religious faith and believed strongly in the sanctity of life. They clearly stated that, should their baby breathe after birth they would like all measures to preserve her life to be taken and requested the neonatal team to be present at the delivery. A baby girl named Beth, weighing 450 g (1lb) was delivered four hours later; she was resuscitated and taken to the neonatal unit. She required maximal intensive care for three days before she began to improve. On ultrasound scan it was clear she had suffered a major brain injury on one side which carried a greater than 90% risk of cerebral palsy developing. Her parents requested that intensive care should be continued because they believed everything possible should be done to keep Beth alive. Beth required two surgical operations to correct bowel problems, and received oxygen treatment for six months.

After two years her parents returned for follow up. Beth had severe cerebral palsy and was only just sitting up (normally achieved by nine months), she could feed herself a biscuit and she had two words in her vocabulary. Her parents were pleased with her progress and reaffirmed that, for them, their original decision was right.

Sanctity of life

5.32 For Beth’s parents the likely degree of disability and their own capacity to deal with it was not a major concern. Their belief that everything possible should be done to enable Beth to survive came from their strong reverence for the sanctity of life (paragraph 2.9), a view consistent with the teachings of their religion. Crucially, they were content with the decision in retrospect. For Beth’s parents considerations about best interests were not incompatible with her condition and their own religious outlook.

5.33 Beth’s parents may have been counselled by a religious adviser. The main question for them would be not whether Beth’s life was worth living but how it should best be respected. The adviser would see it as part of his or her role to help disentangle any conflicting values that parents might be experiencing, although in this case the parents were clear from the outset. An unavoidable problem in seeking to interpret religious writings to guide a couple is that the situation in which they find themselves is far removed from the context in which the writings were developed.

5.34 In this case, the parents’ views were possibly inconsistent with the doctor’s assessment of the best interests of the baby, but he nevertheless agreed to do all he could for Beth. This illustrates the importance of ensuring that there is sufficient sensitivity about the respective positions from both sides. In paragraph 3.14 the Working Party noted that doctors and nurses sometimes have to come to terms with decisions that are different from the choices they would have made for themselves and might find specific professional training beneficial to help them understand the perspective of parents and to communicate effectively with them.

Understanding prognoses

5.35 When parents are asked whether their baby should be resuscitated, they have to assess two main risks: first that of a baby dying after a period of intensive care, and secondly, the possibility of survival with disability. In the initial assessment of whether a baby may survive, less attention is given to the potential pain and distress for the baby caused by a period of unsuccessful

55 A situation where the neck of the womb (cervix) does not close tightly, increasing the risk of infection, ruptured membranes and early labour.

56 Personal communication, fact-finding meeting with the Working Party.
intensive care. Parents vary in their response to such a situation. For example, some parents are acutely concerned about the clinical effort required to support a child in intensive care and weigh the need for it against the chances of survival. They may conclude that they cannot subject their baby to so many procedures when he or she is likely to die. Other parents may need the reassurance that all options have been tried to assist their baby to survive, including intensive care.

5.36 In assessing the risks for Beth there may be confusion about what is meant by ‘disability’ and the extent to which the interests of the child are balanced with the interests of the family. One of the most important considerations at the borderline of viability is attitude to risk. Parents, like most people, often have difficulty in interpreting statistics about risk. They can make very different judgements about the relevance of statistics to their particular situation, especially at such a stressful time. For example, some couples might not accept a 50% risk of serious disability because of fears that they would be unable to cope with caring for a disabled child. Their perception may be different if the risk was expressed another way: that there was a one in two chance that their baby would be free from serious disability. Other parents might pin their hopes on any chance of survival, no matter how small, either disregarding or accepting the consequences. The Working Party found that although general guidance is available from the Royal Colleges and other bodies (see Appendix 9), there is an absence of written information or other aids to communication on prematurity, in particular describing possible outcomes for babies of particular gestations, together with the risks. Such information might be provided for parents where difficulties have been diagnosed during pregnancy. The Working Party therefore recommends that a pregnant woman who presents with an imminent extremely premature birth should be given written information on prematurity, explaining the risks and the procedures that will occur. It should include information on the issues and decisions that she may encounter, so that she, if she is not too distressed or too ill, her partner or other family members, can begin to familiarise themselves with the issues. The information should be supported by the opportunity for face to face discussion. Consideration should also be given to making such information available, on request, to all pregnant women earlier in pregnancy. Any information should be available in different languages and mediums to meet the needs of different individuals, as described in the National Service Framework Standards.57

Perceptions of disability

5.37 Parents and the professionals who advise them often perceive disability in different ways. This difference of view is also reflected in the published literature.58 Many studies measure the performance of children who were born extremely or very prematurely, against children born at full term in order to understand the impact that premature birth has on childhood development. This research is important as it indicates the nature and extent of the effect of premature birth and of its complications; it may also help doctors understand the impact that treatment after birth can have on the developing child. However, these studies will tend to emphasise a ‘worst case scenario’ by pooling data on serious disabilities with data on those that are less serious. What is rarely done is to distil from these data those outcomes that parents or professionals would consider to not be in the child’s best interests. Often these are the conditions labelled as severe or moderate disabilities. These conditions are less common than


is often thought. Other studies try to evaluate the ‘quality of life’ using either self-report or ‘proxy’ measures completed by parents or other people involved in the child’s life. Generally and significantly, a child often reports his or her health state more positively than his or her carers (see paragraph 7.9) and this view is borne out by studies that have reported adult outcomes for very low birthweight or extremely low birthweight survivors. Survivors may have more health problems and achieve less academically but those without the most serious impairments generally integrate well into society. Thus professionals and parents who are in discussion about an extremely premature birth must be clear what is meant by the terms ‘quality of life’ used to convey the likely nature of any disability.

5.38 Beth’s parents were advised during the pregnancy that if their baby survived, there was a high risk of disability. Ultrasound diagnosis after the birth showed those risks to have increased to 90%. Their faith was a crucial factor in leading them to press for every possible step to be taken to preserve life, despite the high risk of Beth developing cerebral palsy. The loss of two previous pregnancies, and the fact that the mother was older, may have also been influential. The doctors followed the parents’ wishes, though they themselves might have made different choices because they held different ethical and/or religious beliefs.

5.39 Although Beth did not do as well as her parents had hoped, she had survived and could experience human relationships. It is less likely that she would have been resuscitated in the Netherlands because of the practice of limiting resuscitation for babies born before 25 weeks of gestation (see Box 8.1). Even in the UK, it is possible that, had Beth been born in a different hospital or the treating clinicians had held different views, her outcome might have taken a different turn. This variability in practice suggests a more systematic approach to decision making on resuscitation should be adopted in the UK. Such an approach should take into account the genuine uncertainty over outcome for babies at the borderline of viability in terms of moderate or severe disability if they should survive resuscitation (see paragraph 5.16). The most important point to communicate at the borderline of viability is that between 23 weeks and 25 weeks, six days of gestation, while survival is possible, the future for some children is bleak, yet for others it is not and doctors cannot reliably predict which group a surviving baby would fall into (see paragraphs 5.13–5.18). For parents, the primary concern is their own baby. This is the basis of our conclusion that under certain circumstances, parents should be offered the opportunity to choose whether or not a baby is resuscitated. In Chapter 9 we develop guidelines on resuscitation and criteria to help establish the best interests of the baby. The Working Party recommends that written information about health outcomes for premature babies should be provided for families, to be used in addition to verbal advice. This information would also support junior members of the clinical team who might not have the benefit of experience when having to advise on resuscitation. We suggest too, that specific training may assist doctors to achieve a deeper understanding and to avoid being unintentionally directive when counselling parents.


Legal issues

5.40 Beth’s case does not present any legal dilemmas. The doctors accepted her parents’ wishes that their daughter should be given every opportunity to survive, and their view that this would be in her best interests. Had they concluded that it would not be in Beth’s best interests to provide intensive care, they would have needed very strong grounds for this conclusion and would probably have had to go to court to argue that she should not be resuscitated and actively treated despite her parents’ wishes to the contrary. We consider later the case of baby MB (paragraphs 8.35–8.36) whose condition was more serious than Beth’s, where a judge endorsed the decision by the parents to keep him alive. In Beth’s case, the outcome appears to suggest that from the present perspective of the parents, the original decisions taken were the right ones. However, there is a possibility that Beth’s disabilities could in the future become so burdensome that the parents might feel that it had been wrong to resuscitate her.

Case 5: Callum – decision making when the parents disagree

Callum

A 21-year-old woman was admitted in early labour at 23 weeks, three days of gestation. The obstetrician explained to the woman and her partner that the estimated chances of a child surviving without moderate or serious disability were only 3% at the current gestation but would increase over the next week to about 20%. They discussed whether or not they should treat the woman with two injections of steroids to enhance the baby’s chances if labour progressed.

The woman considered the risk of the child being disabled to be high but wanted to try and help her child after the birth. Her partner was adamant that he did not want any intensive care to be offered after birth unless the baby was delivered later, when the chances of a normal outcome were better; he had a sibling with Down’s syndrome and did not want the long-term responsibility of caring for a child with disability.

The couple could not agree on a course of action. The woman was given two doses of steroids; they were then counselled by the neonatologist but neither parent changed their stance. Their baby, named Callum, was delivered at 24 weeks of gestation. The neonatal team offered intensive care because the couple could not agree a course of action and the steroid injections had been given to optimise outcome. The child, despite a difficult neonatal course, had a normal brain scan and at two years was free from cerebral palsy and had a developmental score in the normal range. The parents separated two months after Callum was discharged home.

Best interests

5.41 As we have observed above, consideration of the best interests of all involved in the decision-making process is crucial in critical care decisions. The usual assumption is that it is in a child’s best interests to survive and that this has the greatest weight or is paramount. However, we have given reasons why a balancing of all interests of those involved is required (paragraphs 2.28–2.30). The case of Callum puts the feasibility of this proposal to the test as there are a number of competing interests. The mother focuses on the child’s best interest, is conscious of her responsibility towards him and seeks to promote his chances of survival in every way. The father, by contrast, focuses on previous experience with his sibling. Independent of the nature of any disability by which Callum might be affected, he believes that having a healthy child should be the guiding principle, contrary to what might be in the child’s, or his partner’s best interest. The healthcare team decides to give priority to the mother’s wishes. In cases of disagreement between parents about treatment for a baby there is often a presumption in favour of life. This can have the advantage of allowing more time for differences to be resolved. However, we have argued that there may be circumstances when it is in the best interests of a newborn baby that his or her life should not be actively supported if born alive (paragraph 2.11).
Decision making

5.42 As the limitations of applying the principle of best interests above have shown, there are many occasions where no consensus is attainable. How should decisions be made in these cases? One way of resolving this question would be to focus on cases where parents disagree solely on the best interests of the child. However, an important constraint on any option seeking to promote Callum’s life is the requirement that invasive interventions require the consent of a pregnant woman, who cannot be coerced to promote the health of her child (paragraph 8.4). It is therefore imperative that advice by the medical team is non-directional and non-coercive.

5.43 However, Callum’s case also shows that when the clinical team follow the wishes of the mother, the conflict may be made worse, as the father might feel excluded. This example raises the question of how a father’s view should be taken into account when it differs from that of the mother. Possibly in Callum’s case, if there had been time to offer independent counselling, one parent might have come to see the other’s point of view. Cultural factors may have an influence. For example, in France we were told that mothers sometimes give way to the father’s wishes for the sake of their relationship.62 Callum’s father had strong opinions that were clearly influenced by his past experiences of family life. We noted earlier that parents’ views may also be affected by many factors, such as their expectations of parenthood, their attitude towards illness and disability, and values influenced by religious faith (see paragraph 3.17). Socio-demographic factors including age, educational background, ethnic origin and household income are also influential (see also paragraph 4.32).

Legal issues

5.44 The decision about whether or not to accept steroid treatment is in law entirely a matter for the pregnant woman. Her partner cannot force her to accept his viewpoint. Once Callum is born, if his parents are married or register the birth together, they share parental responsibility for their new baby. Consent from one parent would be sufficient to authorise Callum’s treatment and doctors can therefore proceed on the basis of Callum’s mother’s wishes. Often though, if parents disagree, or if doctors have a clearly different judgement about a baby’s best interests, the courts may become involved. In principle, an emergency application to the court could be sought, but this would depend on whether there were any clinical measures that could be taken to keep Callum alive while the judge considered the case. Generally, however, in cases like that of Callum, decisions have to be made so swiftly that resort to court may not be feasible.

Economic issues at the borderline of viability

5.45 Resource constraints are frequently cited as important in determining whether the costs of providing intensive care to babies born at the borderline of viability can be met by the NHS. Neonatal intensive care is often described as a high-technology, high-cost and low-volume service compared with other health services.63 Babies born at the borderline of viability who survive may spend protracted periods in hospital as discharge usually occurs around the original expected date of delivery; stays of 16 weeks are therefore not uncommon. This

63 The total spending by Primary Care Trusts in England on neonatal conditions in 2004/5 was approximately £750 million, which amounts to 1.3% of their total budget. For comparison, the disease area with the largest spend was mental health, which received ten times the amount for neonatal conditions, while the lowest spend was just over £300 million for hearing disorders. Department of Health (2006) 2004–5 National Programme Budgeting Data, available at: http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/ProgrammeBudgeting/fs/en, accessed on: 17 Aug 2006; King’s Fund (2006) Briefing – Local variations in NHS spending priorities, available at: http://www.kingsfund.org.uk/resources/briefings/local_variations.html, accessed on: 17 Aug 2006.
particular group of babies has the highest risk of conditions for which a prolonged period of intensive care is needed. This is reflected in the net economic cost of the initial admission for care after birth being on average highest in the least developmentally mature babies. For example, in a recent review of economic analyses of neonatal care, initial health service costs for babies born at less than 1,000 g were found to be 75% higher, on average, than for those born at 1,000–1,499 g. Costs have been shown to be significantly higher in studies performed in North America compared with other countries.

5.46 To these costs must be added health service costs incurred after discharge from hospital (see Table 5.2). Children born prematurely are frequently readmitted to hospital in their early years, incurring significant additional health service costs (estimated for children born before 28 weeks in the former Oxford region at an average additional cost of £14,600 each over the first five years of life compared with children born at term). In Merseyside, health service costs for infants of different birthweight groups who were followed up for eight to nine years were approximately £14,000 for the lowest birthweight group (≤ 1,000 g), £12,000 for the intermediate birthweight group (1,001–1,500 g) and £7,000 for the highest birthweight group (1,501–2,000 g) at 1998 prices. Even without disability, with low birthweights (≤ 2,000 g), children used hospital and family practitioner services about five times more throughout the follow-up period than children in a group of controls, matched for age, sex and school class. This differential increased to 16-fold among the lowest birthweight group. Research elsewhere in England supports these trends.

5.47 We are not aware of any published studies comparing the continuing health-related costs for treating children born at the borderline of viability with those of treating children with other conditions. We have therefore provided a few examples that may give some perspective.

| Table 5.2: Mean health and societal costs for children in the EPICure Study over 12 months at six years of age* |
|--------------------------------------------------|---------------------------------|
| Cost category                                   | Mean cost per child (UK£, 2003 prices) |
|                                                 | Group of 241 children born extremely prematurely | Control group of 160 children born at full term |
| Hospital inpatient care costs                   | 605                                            | 116                                           |
| Hospital outpatient and day care costs          | 255                                            | 53                                            |
| Community health and social care costs          | 422                                            | 104                                           |
| Drug/medication costs                           | 10                                             | 3                                             |
| Education costs                                 | 3470                                           |                                                |
| Additional family expenses                      | 573                                            | 120                                           |
| Indirect costs                                  | 56                                             | 17                                            |
| Total                                           | 9541                                           | 3883                                          |


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Healthcare costs for epilepsy, based on studies of children and/or adults in the UK, France, Italy and Germany, have been found to average between US$100 and US$3,000 (£60–£1,800) per individual per year, depending particularly on frequency of seizures. For children with autism, health-related costs were found to be in the region of £1,300–£2,300 per year (based on 1997/98 prices), depending on whether an additional learning disability was present. These studies each use different methods to calculate costs and include different components as ‘health’ costs, so that it is difficult to compare them directly. Nevertheless, it would appear from these findings that the ongoing health-related costs for children who survive following extremely premature birth are comparable with those for some other conditions that can occur during childhood.

5.48 Beyond the health service, there are societal costs to be considered. For healthy six-year-old schoolchildren in their seventh year, the total costs have been calculated at £3,883 for a whole year; in contrast a baby born at 25 weeks accrued £8,000 costs and a baby born before 25 weeks, £12,000. Again, it is clear that the greatest costs were incurred by those babies who were least developmentally mature at birth, as has been found elsewhere.

5.49 While the costs of health services are likely to diminish over the subsequent years of life, the need for additional support at school for many extremely premature survivors with cognitive and other impairments is substantial. If we compare educational costs for extremely premature babies with those for babies born at term, we find that an extra £4,150 was incurred during their seventh year, for babies enrolled into the EPICure Study (see paragraphs 5.7–5.11).

5.50 The financial costs incurred directly by a family to meet additional expenses incurred as a result of a child’s disability seem relatively modest (£453 per year on average in the EPICure cohort), but these costs are greatest in those with the most social disadvantage and thus cannot be ignored. In practice the economic burden after leaving the neonatal unit is not evenly distributed, as a small proportion of survivors require substantial support, whereas the majority of families incur only modest costs above those of routine family life. The total economic burden for healthcare and other costs incurred as a result of survival after birth at borderline viability is likely to increase if more babies of extremely low gestation survive, because although the proportion of babies born at a given gestational age who develop disabilities may decline, the total numbers may increase. It should not be discounted, however, that interventions to reduce impairment in this group may have significant economic benefit throughout childhood and into adult life.

5.51 The success of neonatal intensive care has increased the pressure on resources allocated to neonatal services. For birth at the borderline of viability, long periods of intensive care and hospital stay are required. Most neonatal units to which babies are referred from other hospitals run at close to maximal capacity because of high demand. Nearly all the units that

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69 Jarbrink K and Knapp M (2001) The economic impact of autism in Britain Autism 5: 7–22. Health-related costs were taken to be costs of medication, hospital and other health and social services.
70 The definition of ‘societal costs’ used by the researchers was broad and encompasses impacts on social, educational and other sectors, and on families and carers. The data collected included the child’s use of hospital and community health services, social services and education services, time taken off work by parents and informal carers as a result of the child’s ill-health and broader societal impacts that could be attributed to the child’s disability, such as additional expenses on food, bedding and child care.
74 Ibid.
responded to a recent survey reported admitting more babies than they had resources or staff for, and 72% reported that they had been closed to admissions at some stage during the previous six months. In the Trent region, one extra neonatal cot (including the cost of staffing that cot) was required each year over the past ten years to allow for extra activity. The main reason, however, for pressure on cot availability in neonatal intensive care is a shortfall in the number of nurses available to provide the recommended level of one-to-one nursing. Constraints in provision may not always allow healthcare professionals to do what they judge to be best for each and every child, and situations such as the need to transfer a baby to another hospital have to be managed. Notwithstanding such constraints, we concluded in Chapter 2 that decisions at the microeconomic or individual level should still be determined, not by resource considerations, but by clinical judgements of priority, which take into account the best interests of all babies involved.