

**Perinatal management of extreme preterm birth before 27 weeks of
gestation:
A Framework for Practice**



**British Association of
Perinatal Medicine**

**In conjunction with the Royal Colleges of Obstetricians and Gynaecologists and Paediatrics and Child Health,
the British Maternal and Fetal Medicine Society, the Royal College of Nursing, the Royal College of
Midwifery, MBRRACE-UK, Bliss and Sands**

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EXECUTIVE SUMMARY

1. This Framework has been developed by a multidisciplinary working group in the light of evidence of improving outcomes for babies born before 27 weeks of gestation, and changes in the approach to their care.
2. Management of labour, birth and the immediate neonatal period should reflect the wishes and values of the mother and her partner, informed by consultation with obstetric and neonatal professionals.
3. Whenever possible, extreme preterm birth should be managed in a maternity facility co-located with a NICU.
4. Active management of labour and neonatal stabilisation may be considered for babies born from 22⁺⁰ weeks of gestation.
5. Decision making for babies born before 27 weeks of gestation should not be based on gestational age alone, but on assessment of the baby's prognosis taking into account multiple factors. Decisions should be made with input from obstetric and neonatal teams in the relevant tertiary centre if transfer is being contemplated.
6. Risk assessment should be performed with the aim of stratifying the chance of a poor outcome into three groups: extremely high risk, moderate to high risk, and lower risk.
7. For fetuses/babies at moderate to high risk of poor outcome, the decision to provide either active management or palliative care should be based primarily on the wishes of the parents.
8. If life-sustaining treatment for the baby is anticipated, pregnancy and delivery should be managed with the aim of optimising the baby's condition at birth.
9. Conversations with parents should be clearly documented and care taken to ensure the agreed management plan is communicated between professionals and staff shifts.
10. Decisions and management should be regularly reviewed before and after birth in conjunction with the parents, and reconsidered if the risk for the fetus/baby changes, or if parental wishes change.

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INTRODUCTION

1. Care of the baby, woman and family around the time of an extremely preterm birth is one of the most challenging aspects of perinatal medicine, both for clinicians and families. In 2006, the Nuffield Council on Bioethics convened a working group to explore the ethical, social, economic and legal issues around clinical decisions made in fetal and neonatal medicine ⁽¹⁾; in response to their report the British Association of Perinatal Medicine (BAPM), in conjunction with other professional groups, developed a Framework for Clinical Practice for the Management of Babies born Extremely Preterm at less than 26 weeks of gestation. These documents were based largely on data from the original EPICure study in 1995 of births before 26 weeks of gestation, with some additional preliminary data from EPICure 2 regarding babies born in 2006 before 27 weeks of gestation ^(2,3). Subsequently, the Royal College of Obstetricians and Gynaecologists (RCOG) developed a scientific position paper about the management of delivery at the threshold of viability ⁽⁴⁾.
2. Advances in perinatal care have led to steadily improving outcomes for babies admitted to English neonatal intensive care units (NICUs), particularly at the lowest gestational ages, and in the current era, the outcomes for babies actively managed at 22 weeks of gestation appear similar to those of babies at 23 weeks of gestation at the time of the 2008 BAPM Framework for Clinical Practice ⁽⁵⁻⁸⁾. Reports from other countries confirm increasing survival and improving neurodevelopmental outcome for babies born before 27 weeks of gestation ⁽⁹⁻¹²⁾. Although internationally there remain differences in practice, there is increasing willingness to consider stabilisation at birth and subsequent intensive care for extremely preterm babies ⁽¹³⁻¹⁵⁾, accompanied by greater acknowledgement of the importance of involving parents in perinatal decision making ⁽¹⁶⁾. Reported outcomes are, of course, impacted by willingness to consider active interventions before and after birth ⁽¹⁷⁾.
3. This updated Framework for Practice has been developed by consensus, taking into account the most recent available outcome data, both from the UK and internationally. We are grateful for input from the RCOG, the Royal College of Midwives and the Royal College of Nursing, the British Maternal Fetal Medicine Society, the Royal College of Paediatrics and Child Health, MBRRACE-UK, neonatal nurse associations and parent representative organisations, including Bliss and Sands. The scope has been extended to include births up to 26⁺⁶ weeks of gestation, better to align with national recommendations and published data, and we refer to new RCPCH and other national guidance on palliative care of babies, as well as guidance on bereavement care for parents who experience loss of a baby ^(18,19).
4. Prevention of preterm birth is now a national priority, and all maternity services should ensure that measures are in place to realise this ambition. National guidance is available to enable prevention strategies; this guidance not only addresses prevention, but also interventions to optimise outcomes for babies born too soon ⁽²⁰⁻²²⁾.
5. Perinatal care at extremely preterm gestations will always need to be individualised and should be led by senior staff in midwifery, obstetrics and neonatology. Parents must be included in discussions about perinatal care, and their hopes and expectations explored with honesty and compassion in a realistic way. Decisions should be made together with parents, based on the best available evidence about the prognosis for the individual baby. It is essential that such decisions reflect all relevant prognostic information and not simply gestational age.

REMIT

6. The purpose of this Framework for Practice is to assist decision-making relating to perinatal care and preterm delivery at 26 weeks and 6 days of gestation or less in the United Kingdom. It does not relate to decision-making around termination of pregnancy.
7. The Framework for Practice is aimed primarily at professionals, but will be freely available via the BAPM website. We have included guidance designed to assist health professionals in communicating with parents about the issues and information contained within this document. It is emphasised that each case will be unique, and that

communication must always be tailored accordingly.

DEFINITIONS

8. In the UK, a **stillbirth** is legally defined as the birth of a baby with no signs of life at, or after, 24 completed weeks of gestation.
9. For consistency, we have used the term “**fetus**” to describe the baby before birth, and “**baby**” after birth. Within the document “**parents**” refers to the mother and her partner.
10. We define “**active**” care where both obstetric and neonatal management have the aim of sustaining life for the baby, and “**palliative**” care as all relevant obstetric and neonatal management when it has been agreed that the instigation of potentially life-sustaining treatment for the baby would not be appropriate.

RISK-BASED APPROACH TO DECISION-MAKING

11. A key ethical consideration for decisions about instituting life-sustaining treatment for an extremely preterm baby is the baby’s prognosis – the risk of an acceptable (or unacceptable) outcome if active management is undertaken. If there is a plan to provide life-sustaining treatment for the baby, then it follows that the pregnancy and birth should be managed with the aim of optimising the baby’s condition at birth.
12. We advise a stepwise approach to decision-making, involving two key stages:
 13. Assessment of the risk for the baby if delivery occurs, incorporating both gestational age and factors affecting fetal and/or maternal health.
 14. Counselling parents, and involving them in decision-making.

Assessment of the risk for the baby

1a. Gestation-based risk assessment, including both mortality and survival with severe impairment

15. The earlier the ultrasound dating scan has been carried out, the more accurately gestational age will be known. In accordance with NICE guidelines, all pregnant women in the UK should have been offered an early ultrasound scan between 10⁺⁰ and 13⁺⁶ weeks of gestation, with crown–rump length (CRL) measurement used to determine gestation. This assessment is accurate to within 5 days in 95% of cases ⁽²³⁾. From 14⁺⁰ weeks (CRL > 84mm), gestation should be estimated from fetal head circumference; the estimated uncertainty of this gestation prediction is 6-7 days at 14 weeks, rising to 12-14 days by 26 weeks of gestation ⁽²⁴⁾.
16. Survival of extremely preterm babies has increased steadily since 2006, with greater willingness to offer neonatal intensive care. Recent UK data, for babies born in 2016, indicate survival to one year of 38% of live-born babies 23⁺⁰ to 23⁺⁶ weeks of gestation who received active treatment after birth ⁽⁸⁾. The number of surviving babies at 22 weeks of gestation is small, and thus the confidence intervals are wider than at other gestational weeks, but both internationally and in the UK there is a trend towards increasing survival, with reported survival rates of approximately one third in babies who receive active care at birth. At all gestations, survival rates show ongoing improvement ⁽⁶⁾, are higher when the number of live born babies is used as a denominator and are highest when babies who receive palliative care at birth are excluded. Survival to live birth will be influenced by management of labour and birth. As outcomes are changing, management should always be based on the most recent data available; data presented in Appendix 1 are the most up to date data available in June, 2019).

17. The assessment of risk of severely disabling conditions among survivors is fraught with difficulty, not least differences in individual views about acceptable levels of disability. What for one individual or family may be an acceptable outcome may not be acceptable for another. In the absence of regularly updated national data on the prevalence of severe disability after extremely preterm birth, we recommend that the well-established “severe impairment” category, as defined by the 2008 BAPM Working Group, be used to inform parents when discussing risk following extremely preterm birth ⁽²⁵⁾.
- i. The severe impairment category includes any of:
 18. severe cognitive impairment with an IQ lower than 55 (< -3 standard deviation); this will usually result in the need for educational support and require supervision in daily activities
 19. severe cerebral palsy – classified as Gross Motor Function Classification System (GMFCS) grade 3 or greater (Appendix 1)
 20. blindness or profound hearing impairment.
21. The risk of severe impairment increases with increasingly preterm birth, and is currently approximately 25% for babies born at 23 weeks of gestation. Generally, as risk of mortality decreases, the risk of disability among survivors also decreases (Appendix 1).
22. **1b. Modified risk assessment**
23. Accurate information about the current pregnancy, including assessment of both fetal and maternal health should be used to refine gestation-based risk of absolute survival and survival without severe impairment.
24. A range of factors are associated with increased or decreased risk:
 - **Fetal factors** which may increase risk include male sex, multiple pregnancy, congenital anomaly, and poor fetal growth.
 - **Clinical conditions** which pose additional risk and have been associated with increased mortality and morbidity include prolonged pre-labour rupture of membranes before 24 weeks of gestation and clinical evidence of chorioamnionitis. ^(26,27)
 - **Therapeutic strategies:** administration of antenatal steroid and magnesium sulphate are associated with improved survival and neonatal outcomes as well as reduced risk of childhood impairment, even before 24 weeks of gestation. ⁽²⁸⁻³¹⁾
 - **Clinical Setting:** survival is highest at these extreme preterm gestations in centres with experienced staff and higher patient numbers. A strategy of antenatal transfer below 27 weeks of gestation for birth in a maternity unit with a co-located NICU is recommended ^(4,32-33).
25. Following full history taking and risk assessment, the chances of unacceptably poor outcome if life-sustaining care is provided for the baby will generally fall into one of the following categories: extremely high risk; moderate to high risk; lower risk. A proposed visual tool for refinement of risk is illustrated in Figure 1.

1. Assess gestational age – estimate current risk of poor outcome

	Extremely high risk	Moderate-high risk	Lower risk			
Gestational Age	<22	22	23	24	25	26

2. Assess presence of non-modifiable risk factors – adjust risk of poor outcome

	Higher risk	Lower risk
Gestational week	Beginning of week	End of week
Estimated birth weight	Small for GA	Normal for GA
Fetal sex	Male	Female
Singleton/Multiple	Multiple	Singleton

3. Assess modifiable risk factors – adjust risk of poor outcome

	Higher risk	Lower risk	
Antenatal steroids	No	Incomplete	Yes
Place of birth	Outborn (non tertiary NICU)	Inborn (tertiary NICU)	

26. Figure 1: Proposed visual tool for refinement of risk

Box 1 represents the consensus of the Working Group in regard to risk categories for the purposes of this framework.

Extremely high risk: The Working Group considered that babies with a > 90% chance of either dying or surviving with severe impairment if active care is instigated would fit into this category. For example, this would include:

- all babies < 22⁺⁰ weeks of gestation (i.e. up to 21⁺⁶ weeks of gestation)
- some babies at 22⁺⁰ - 23⁺⁶ weeks of gestation (for example those with unfavourable risk factors)
- some severely growth restricted babies ≥ 24⁺⁰ weeks of gestation
- some babies with severe co-morbidities, including acute fetal compromise

Moderate to high risk: The Working Group considered that babies with a 50-90% chance of either dying or surviving with severe impairment if active care is instituted would fit into this category. For example, this would include:

- some babies at 22⁺⁰ - 23⁺⁶ weeks of gestation
- some babies ≥ 24⁺⁰ weeks of gestation with unfavourable risk factors or co-morbidities

Lower risk: The Working Group considered that babies with a < 50% chance of either dying or surviving with severe impairment if active care is instituted would fit into this category. For example, this would include:

- most babies ≥ 24⁺⁰ weeks of gestation
- some babies at 23⁺⁰ – 23⁺⁶ weeks of gestation with favourable risk factors

27. There is no objective way of defining a risk as ‘extremely high’ *versus* ‘moderate to high’ and families differ in the outcome that they regard as unacceptably poor. Thus counselling should include assessment of the parents’ knowledge, views and values. For women presenting to a non-tertiary maternity and neonatal centre, assessment of risk should include early discussion with the relevant tertiary centre. It is important that parents are offered choices and supported to make decisions appropriate for their individual preferences. For pregnancies from 22⁺⁰ weeks of gestation decisions should not be based on gestational age alone. Within a multiple pregnancy, the risk may differ between fetuses, and so each should be considered as an individual. This may mean that appropriate management is not the same for each baby.
28. The agreed risk for the baby has ethical and practical implications for the options that should be available.
29. **Extremely high risk:** For babies with an extremely high chance of death or of survival with unacceptably severe impairment, palliative care would usually be in the best interests of the baby and life-sustaining treatment would not usually be offered. There is no absolute indication for paediatric attendance at the birth, although for individual families this may be helpful.
30. **Moderate to high risk:** For babies with a moderate to high chance of death, or of surviving with unacceptably severe impairment despite treatment, it is uncertain whether active care is in the best interests of the baby and their family. Parents should be counselled carefully and parental wishes should inform a joint decision to provide either active or palliative treatment. Ideally, a senior neonatal clinician who has previously met the parents will be available to attend the birth and supervise implementation of the agreed plan.
31. **Lower risk:** For babies with a lower chance of death, or of survival with unacceptably severe impairment, active management would usually be considered to be in the best interests of the baby. A senior neonatal clinician should attend the birth.
32. **Counselling parents and decision-making**
33. Whenever possible both parents should be present when planning an extremely preterm birth. The planning consultation should include senior clinical staff from the obstetric, midwifery and neonatal teams who will be caring for the mother and her baby before, during and after the birth.
34. The assessed category of risk to the baby should be conveyed sympathetically but unambiguously, and the hopes and expectations of parents explored with honesty and compassion in a realistic way. Clear, balanced information should be shared, and management options discussed. Time should be allowed for clarification and questions, and parents offered the opportunity to revisit discussions with the perinatal team at any point, acknowledging the challenging nature of the information that they are being asked to receive and the decisions that are being made.
35. *In utero* transfer to a maternity facility co-located with a NICU should be considered at the earliest opportunity when active management is planned ^(4,32). Parents should be made aware that the prognosis (and therefore management) may be revised following *in utero* transfer to a centre with greater experience of managing extremely preterm birth (*e.g.* following detailed ultrasound scanning).
36. Communication and agreed plans must be documented in full and, when relevant, clearly communicated with the receiving centre. The agreed plan of management should be revised regularly if pregnancy continues.
37. When active care is planned and time allows, parents should be given an opportunity to visit the neonatal unit and to meet staff, and should receive information and support regarding expressing breast milk.

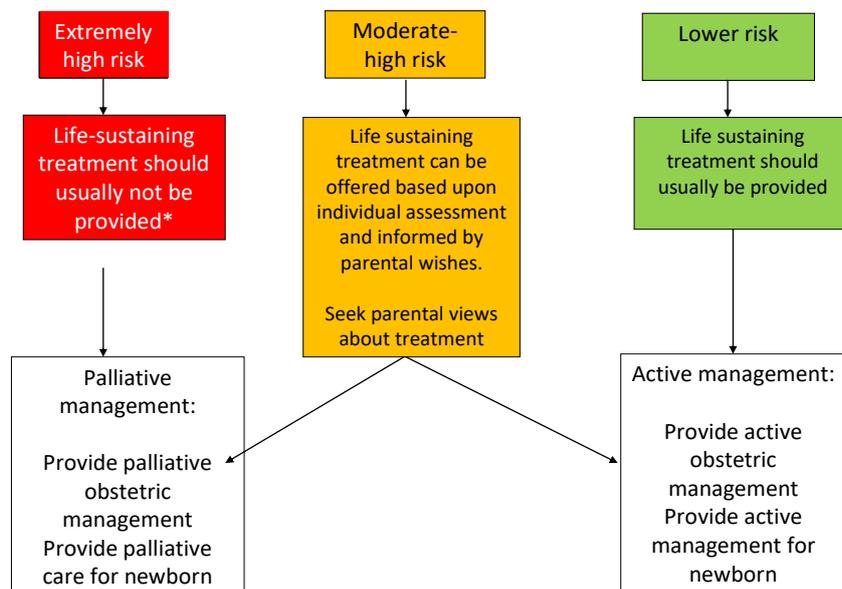
38. Where appropriate, the practicalities of commencing, withholding and/or withdrawing intensive care, and the positive role of palliative care strategies should be described to the parents. This will help prepare them for possible outcomes after the birth. Parents may find the advice and support of their family, friends, spiritual advisers and/or local and national support organisations to be of great value at this time and should be signposted appropriately.

39. SUBSEQUENT MANAGEMENT

40. Following consultation with parents, management of the birth will follow one of two pathways: “active” or “palliative” (Figure 2). Consistency in obstetric and neonatal management is essential, either to ensure that the baby is born in the best possible condition, or to avoid unnecessary intervention.

41. The challenges inherent in making a binary decision from a continuum of risk should not be underestimated, and categorisation of risk should always be undertaken by the most senior clinicians available. Electronic risk calculators may be of value but care should be taken to ensure they are populated with the most recent data, and include options for different denominator populations.

42. Figure 2. Decision-making around management of delivery, following risk assessment and after consultation with parents.



*However, assess for modifiable risk factors and reassess risk if/when circumstances change

43. Obstetric management

Active obstetric management

44. When it has been agreed that active care for the baby is appropriate, active obstetric management is important to ensure the baby is born in the best possible condition. An individualised package of obstetric intervention should be offered in all cases where a commitment to active neonatal care has been made ^(4,34). The potential for each component intervention to optimise the condition of the individual baby at birth must be considered, and

not excluded on the basis of gestational age alone.

45. The package of active care to be offered to parents may include the following:

- antenatal steroids
- tocolysis
- antenatal transfer to a tertiary obstetric centre co-located with a NICU
- magnesium sulphate for neuroprotection
- intrapartum fetal heart rate monitoring
- caesarean section (if potential benefits are considered to outweigh risks)
- delayed cord clamping

46. There is little controversy regarding the use of antenatal corticosteroids and tocolysis when birth is highly likely, and there is similarly clear evidence of the benefits of magnesium sulphate and delayed cord clamping.

47. *In utero* transfer to a tertiary centre optimises outcomes for the baby, is better than *ex utero* transfer and is now a prioritised NHS England recommendation ⁽²¹⁾. While the majority of women presenting in threatened preterm labour before 27 weeks of gestation do not deliver in the subsequent 24 hours, there is currently no proven test which accurately predicts preterm delivery. Transfer may present challenges for the family as well as obstetric and ambulance services, but the consensus working group strongly recommends that this is considered at the earliest opportunity. A decision for antenatal transfer must include discussion with the relevant tertiary centre and careful risk assessment by the most senior obstetrician available, to ensure that the mother is fit for transfer, and to avoid birth in transit. In some cases, poor maternal health and/or advanced stage of labour may mean that *in utero* transfer is not the safest option.

48. There is no evidence to inform fetal heart rate monitoring below 26 weeks of gestation ⁽²⁰⁾. Autonomic immaturity at gestations below 26 weeks makes interpretation of continuous electronic fetal heart rate monitoring (CEFM) difficult and there is no evidence that CEFM improves outcomes of preterm labour for mother or baby compared to intermittent auscultation (IA). A senior obstetrician should be involved in decisions around fetal heart rate monitoring below 26 weeks of gestation, and the family made aware of the rationale for fetal heart rate monitoring (or not). CEFM should not be offered before 26 weeks of gestation or if caesarean section is not part of the package of care being implemented (either if parents have declined caesarean section or it is considered that the risks of caesarean section outweigh any potential benefits). From 26⁺⁰ weeks of gestation, intrapartum fetal monitoring (CEFM or IA) should be employed if active obstetric intervention is being undertaken.

49. The most controversial element of active obstetric care is mode of birth. In the majority of extremely preterm births the mother presents in spontaneous labour and delivers with little in the way of complications. Less commonly, elective preterm delivery is necessary for maternal (*e.g.* pre-eclampsia, chorioamnionitis) or for fetal reasons (*e.g.* severe fetal growth restriction); in such cases, delivery by caesarean section may be the only option to ensure timely delivery for mother and/or baby.

50. While caesarean section may be considered less traumatic for the baby, the evidence supporting caesarean section for extremely preterm babies, even in the context of breech presentation, is limited and of poor quality ^(35,36). Extremely preterm caesarean sections can be difficult, and trauma including head entrapment can still occur. Maternal risks and consequences including pain, haemorrhage, infection, thrombosis and injury to bowel and bladder are higher after caesarean section compared to vaginal birth and must be discussed with the mother. There is an impact on future pregnancies in terms of increased risk of uterine rupture and morbidly adherent placenta, and the likelihood of classical caesarean section, with its increased risk of serious maternal complications is greatest at the most preterm gestations ^(36,37). For all these reasons, it is essential that obstetric care is individualised after full discussion between the family and a senior obstetrician along with the neonatal team. There must be clear documentation regarding which elements of active obstetric care will be implemented in each case.

51. Apart from acute indications for intrapartum caesarean section (*e.g.* cord prolapse), and when timely delivery is necessary for mother and/or baby, recourse to delivery by caesarean section (where this has been agreed as the optimal mode of birth), should only occur once labour is established and birth inevitable. It is noted that that even at advanced cervical dilation, birth may not occur for several days. There may be additional benefit to the baby of delaying delivery until birth is unavoidable.

Palliative obstetric management

52. When a decision is made for palliative management of the baby at birth, only interventions for maternal benefit are appropriate. Intrapartum fetal heart rate monitoring is not advised, although IA may be helpful in clarifying expectations around the baby's condition at birth, and be preferable for parents. Parents should be made aware that their baby may gasp or move briefly, or show signs of life after birth.

53. Neonatal Management

Active neonatal management

54. Stabilisation and support for transition should be carried out by, or under the direct supervision of, the most senior member of the neonatal/paediatric team present at the time of birth, and in accordance with Resuscitation Council UK guidance 2015 ⁽³⁸⁾. Ideally this team will be experienced in stabilisation of extremely preterm babies, and led by a consultant neonatologist and/or senior neonatal trainee or experienced ANNP.

55. Delayed cord clamping should be routine practice and particular attention paid to the maintenance of normothermia, with the use of a plastic bag and/or other methods of delivering thermal care, and skin protection. Stabilisation and supported transition with lung inflation, using an appropriately sized facemask, should be initiated.

56. If there is no response to mask ventilation, the baby should be intubated and artificial surfactant administered. The most important intervention is establishment of adequate ventilation. Use of advanced measures for resuscitation including cardiac massage and endotracheal or intravenous adrenaline are rarely required following extreme preterm birth. In the absence of sufficient evidence to justify a different approach in extremely preterm babies, the Working Group recommends applying newborn resuscitation algorithms as used in more mature babies.

57. Effective cardiopulmonary resuscitation for more than five minutes in extremely preterm babies is associated with high rates of mortality and neurodevelopmental impairment ^(39,40); in this scenario, a decision should be made by the most senior experienced attending professional as to when to stop attempts to stabilise the baby.

58. Stabilisation should normally be undertaken in the same room as the parents, who should be offered the opportunity to see, touch and photograph their baby. Following successful stabilisation of the baby, the mother should be supported to express breast milk as early as possible, with ongoing facilitation of parental contact and family involvement as partners in care.

a. Palliative neonatal management

59. Where there is an extremely high chance of a poor outcome for the baby, it would be considered in the best interests of the baby, and standard practice, not to offer neonatal intensive care.

^{60.} Where palliative care is planned, the aim should be to support the parents and their baby, and to avoid interventions that may cause discomfort, pain or separation of the baby from the parents. This care should be delivered in the most appropriate location for the family (which is not necessarily a neonatal unit), and should

therefore not necessitate *in utero* transfer. There must be an emphasis on family centred care, with opportunities for parents to create positive memories of their baby. An Individualised Care Plan should be made in partnership with parents, following guidance within the Perinatal Palliative Care Pathway from Together for Short Lives ⁽¹⁸⁾. Further recommendations may be found in a RCPCH monograph on making decisions to limit treatment in life-limiting and life-threatening conditions ⁽¹⁹⁾. [Link](#).

61. Depending on parents' wishes and service provision, a senior neonatologist or paediatrician may be present at delivery, to provide a brief assessment of the baby's condition at birth, and to support midwifery staff and the family. Respiratory support (including provision of positive pressure ventilation) should not be provided. Parents should be offered the opportunity to hold and to spend as much time as they wish with their baby in a quiet and private location, and they should have been counselled that the baby may show brief reflex movements or signs of life after birth.
62. On average, newborn babies receiving comfort care in the delivery room live for approximately 60 minutes ⁽⁴¹⁾. Supplemental oxygen is not necessary, but could be provided if parents desire.
63. After the baby has died, a parent-led bereavement care plan should be put in place for the family, including communicating with parents and creating memories. Parents should understand what to expect in terms of a review into the care provided during pregnancy and birth using the Perinatal Mortality Review Tool, and the benefits of investigation such as autopsy, to provide as much explanation as possible for the preterm birth and the death of their baby ⁽¹⁸⁾. In England and Scotland this should follow the guidance outlined in the National Bereavement Care Pathway ⁽⁴²⁾; in Wales and Northern Ireland there are locally developed bereavement pathways. Parents should be facilitated to make informed choices, and signposted to support available after they go home.
64. After discharge home, optimal communication with all professionals involved (for example – GP, health visitor, community midwife) is essential. The mother will continue to require postnatal care, and should also receive information and advice about milk suppression or donation. Parents should be offered bereavement counselling, and the opportunity to meet with perinatal staff for a follow up consultation in an outpatient setting. Where possible, this meeting should be conducted by the same staff that counselled the family in the peripartum period. At an appropriate time, the prognosis for future pregnancies should also be discussed.

65. IMPLEMENTATION OF THIS FRAMEWORK FOR PRACTICE

66. A lead person should be identified in each maternity facility responsible for implementation, education, and dissemination of this new Framework for Practice and accompanying parent information.
67. Links to relevant national documents are provided within this document; these should be highlighted and made easily available within each maternity facility.
68. Management of extreme preterm birth and the conversations around this can be exceptionally challenging for staff, so it is recommended that implementation of this Framework into individual units is accompanied by education and training in specific consultation skills. Some guidance is offered in Appendix 3.
69. Networks need to ensure sufficient resource to cope with the predicted number of extreme preterm deliveries, both actual and threatened, and pathways must be in place to ensure appropriate prioritisation and assessment of women likely to deliver extremely preterm. It must never be the case that a newly delivered mother cannot be accommodated in a maternity facility adjacent to her baby.

APPENDICES AND RESOURCES

70. Appendix 1: Outcomes for extremely preterm babies

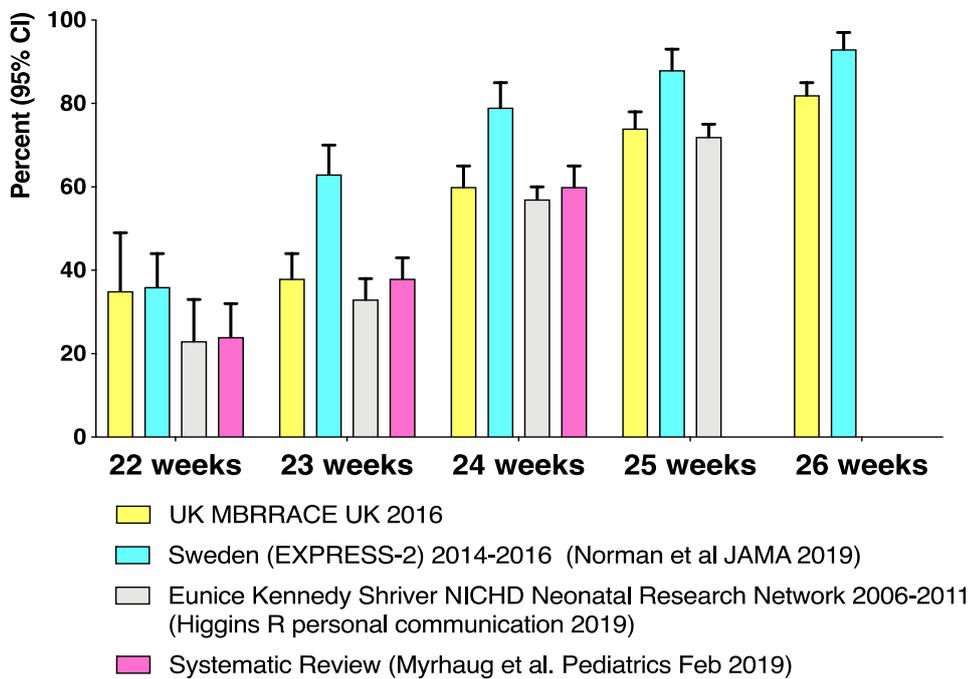
71. Survival/Mortality

72. International studies indicate incremental improvements in survival for the most premature babies over the last 1-2 decades. There is wide variation in survival estimates of live born babies (for example, from 0-37% at 22 weeks, 1-64% at 23 weeks, 31-78% at 24 weeks), influenced by cohort selection, place of birth, and variation in provision of active obstetric and neonatal treatment ⁽⁴³⁾. The largest changes in outcome appear to be at the lowest gestational age. In particular, at 22 weeks' gestation, recent cohort studies from US, Sweden, Germany ⁽⁹⁻¹²⁾ indicate that approximately 30% of liveborn babies who receive active treatment survive to discharge from intensive care.
73. The latest data on outcome for extremely premature babies in Great Britain are presented in Table 1 (source: MBRRACE-UK) ⁽⁸⁾. Survival has increased steadily since 2006 and currently active respiratory care is offered to 88% of babies at 23 weeks and 23% of births at 22 weeks of gestation. Survival at 22 weeks of gestation is based on small numbers of babies and thus the confidence limits are wider than at other gestational weeks. It is also likely that selection of babies for active treatment is biased towards those with best outlook, and so reported survival at 22 weeks of gestation is likely to be higher than would be expected for all babies born at this gestation. Figure 3 displays graphically the estimated survival rates at different gestations for babies who are provided with active care in Great Britain compared to 3 recent publications; this shows that these recent MBRRACE-UK findings are consistent with those in other settings.

75. Table 1: Number and percentage of births, including births where the fetus was alive at onset of labour, live births, births receiving active care, admissions for neonatal care and survival to 1 year of age for births in 2016 in Great Britain. Recording of active care on the MBRRACE-UK database commenced during 2016, and thus rates are inferred from recording of a total of only 292 deaths ⁽⁸⁾.

Gestational Week	22 weeks	23 weeks	24 weeks	25 weeks	26 weeks
All births	486	510	656	664	832
Births alive at onset of labour	290	362	497	508	674
Live births	183	301	456	486	662
% live births alive at onset of labour	63% 57 to 69	83% 79 to 87	92% 90 to 94	96% 94 to 98	98% 97 to 99
Delivery room deaths	155	78	26	19	16
% deaths before admission	85% 80 to 90	26% 21 to 31	6% 4 to 8	4% 2 to 6	2% 1 to 3
Live births receiving active care*	43	264	449	486	662
% live births receiving active care	23%	88%	98%	100%	100%
Admitted for neonatal care	28	223	430	467	646
% admitted for neonatal care (of births receiving active care)	65% 51 to 79	85% 81 to 89	96% 94 to 98	96% 94 to 98	98% 97 to 99
Deaths < 1 year	13	122	160	108	106
Survivors to 1 year	15	101	270	359	540
Survival					
Of those alive in labour	5% 2 to 8	28% 23 to 33	54% 50 to 58	71% 67 to 75	80% 77 to 83
Of live births receiving active care	35% 21 to 49	38% 32 to 44	60% 55 to 65	74% 70 to 78	82% 79 to 85
Of admissions for intensive care	54% 36 to 72	45% 38 to 52	63% 58 to 68	77% 73 to 81	84% 81 to 87

77. Figure 3: Estimated survival (if active care provided), comparing UK with recent international studies (8,9,12)



78. Severe impairment

79. The impact of a particular impairment has ramifications for functioning in many areas and is captured in the WHO International Classification of Functioning, Disability and Health (ICF) ⁽⁴³⁾. Individual perception of the impact of impairment on functioning in society (i.e. disability) is highly personal and varies from family to family, dependent on their experience, knowledge and attitudes, and the support available to them. Indeed, it varies similarly between neonatal doctors and nurses ^(44,45). What for one individual or family may be an acceptable outcome may not be so for another.

80. The criteria for categorisation of impairments in neonatal studies also vary. In 1992, a working party sponsored by the National Perinatal Epidemiology Unit and Oxford Health Authority defined health status at 2 years into severe disability, likely to result in high levels of dependency on others with reduced chances of independent living, or other or no disability. This was refined in the BAPM working group document published in 2008. Other authorities have used a profound category, a subgroup of severe disability, on which to base counselling ⁽⁴⁶⁾. In the absence of regularly updated national data on the prevalence of profound impairments after extremely preterm birth, the working group recommended that the well-established “severe impairment” category as defined by the BAPM Working group ⁽²⁵⁾ be used to inform parents when discussing risk following extremely preterm birth. This has been used in several large population-based studies and gives a reliable estimate of risk not available from local data, where the small number of survivors introduces significant uncertainty into estimates. Generally, for extremely preterm babies, as mortality risk decreases, the risk of severe disability among survivors also decreases.

81. The severe impairment category includes any of:

82. severe cognitive impairment with an IQ lower than 55 (<-3 standard deviation); this will usually result in the need for educational support and require supervision in daily activities

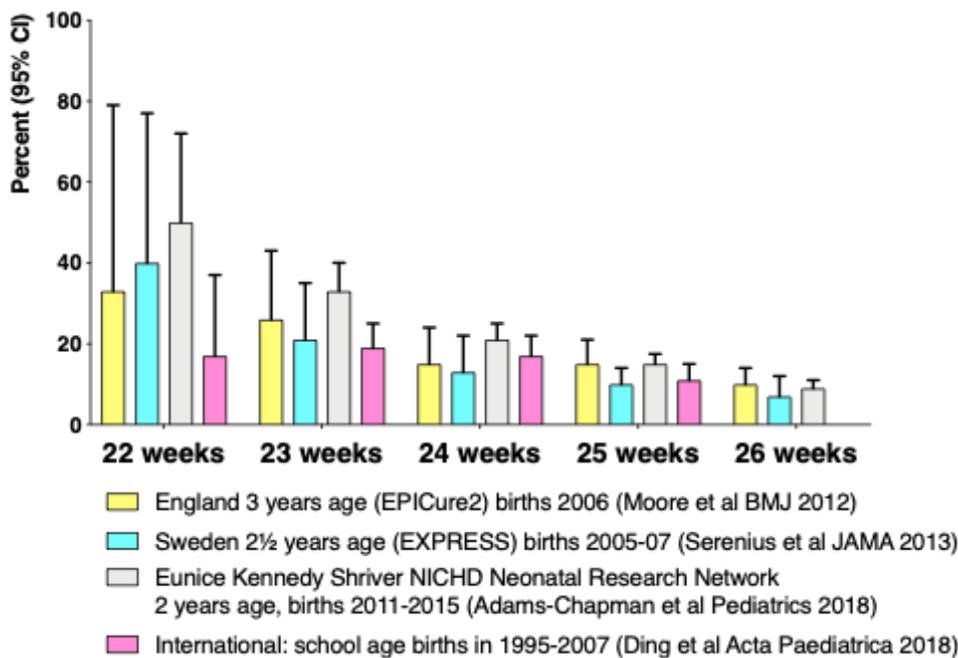
83. severe cerebral palsy – classified as Gross Motor Function Classification System (GMFCS) grade 3 or greater (see Box 2)

84. blindness or profound hearing impairment

85. Estimated prevalence rates of severe impairment in four major studies are shown in Figure 4, which may be summarised as:

- 22⁺⁰-22⁺⁶ weeks: 1-in-3 survivors have severe impairment
- 23⁺⁰-23⁺⁶ weeks: 1-in-4 survivors have severe impairment
- 24⁺⁰-25⁺⁶ weeks: 1-in-7 survivors have severe impairment
- 26⁺⁰ and over: 1-in-10 survivors have severe impairment

86. Figure 4 – Prevalence of severe neurodevelopmental impairment in England (2006) compared with rates reported in 3 recent international publications ^(7,47,48, 49)



87.

88. **Box 2:** GMFCS Grades 3-5 description:

- Level III:** Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.
- Level IV:** Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility

necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

- c. **Level V:** Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self- mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

89. Appendix 2: Situations of uncertainty and potential conflict

90. Uncertain gestational age

91. If gestational age is uncertain, (*i.e.* no dating ultrasound scan) but thought to be $\geq 22^{+0}$ weeks, an ultrasound scan by an experienced sonographer should be carried out if time permits. If the fetal heart is heard during labour, a professional experienced in stabilisation of extremely preterm babies should attend the birth. The baby should be delivered into a plastic bag and an estimate made of gestation. Unless the baby is clearly $< 22^{+0}$ weeks of gestation, and or estimated at < 350 g, stabilisation and supported transition with lung inflation, using an appropriately sized facemask, should begin, usually after one minute of delayed cord clamping. Subsequent management will be dictated by the clinical condition of the baby, the response to stabilisation manoeuvres and parental wishes and expectations. In this scenario it is likely that the parents will have had little, if any, time to consider the situation, so it may be appropriate to proceed with offering neonatal intensive care and reassess the situation in the ensuing hours and days.

92. Rapid birth without time for counselling

93. Preterm labour often progresses rapidly, and there may be insufficient time for detailed discussion with the parents before the baby is born. In such a scenario, a decision about management at birth will need to be made based on the available clinical information and informed by the most recent management plan, if any.
94. When risk is unclear (for example gestation is uncertain), and particularly if there has not been time for full discussion with parents, it would usually be reasonable to embark on a provisional plan of stabilisation +/- resuscitation – providing potentially life-sustaining treatment at delivery, but redirecting to palliative care if the baby appears very immature or responds poorly to stabilisation (for example remains severely bradycardic despite intubation and intermittent positive pressure ventilation). It is noted that assessment of either gestation or risk of poor outcome based on condition at birth is not reliable.

95. Baby born in unexpectedly good condition

96. In the rare circumstance where palliative care has been agreed, but an baby is born in unexpectedly good condition, attending midwifery and/paediatric medical staff should discuss with parents whether the estimated gestation and prognosis were accurate and whether the planned palliative approach is still appropriate.

97. Parents request a second opinion

98. If the parents wish, they should have the opportunity to discuss outcomes with a second senior member of the perinatal team. When parents do not agree with the perinatal team, recently published RCPCH guidance may be helpful ⁽⁵⁰⁾.

99. Threatened birth before 22⁺⁰ weeks of gestation

100. Where gestational age is certain and is below 22⁺⁰ weeks, it would be considered in the best interests of the baby, and standard practice, not to offer neonatal intensive care. If it is possible that the birth may be delayed to a point where active care of the baby would be planned, transfer of the mother to a maternity unit adjacent to a neonatal intensive care unit should be considered.

101. Appendix 3: Communication: Guidance for professionals consulting with families at risk of extreme preterm delivery.

102. This Appendix is designed for use by all staff caring for families at risk of extreme preterm birth, to facilitate the sharing of consistent and accurate information. It should be used to support conversations about decision making with parents, **in conjunction** with written information such as the suggested *Template Parental Information - Helping parents to understand extreme preterm birth* (Appendix 4). Written information should **never** be used as a stand-alone information sharing tool.

103. In order to properly involve parents as equal partners in care and decision-making for their babies, all parents facing potential extreme preterm birth need to understand the risks associated with their baby's birth, and possible treatment options.

104. In the context of the different risk scenarios outlined in this framework, health professionals need to consider how their approach to consulting with parents may differ, depending on the individual circumstances:

105. In **extremely high risk** cases, parents should be provided with relevant information about the risk to their baby, and the recommendation that it is likely to be in the best interests of their baby to offer palliative obstetric and neonatal management. Parents should be told about the role they can play in caring for their baby and memory-making after birth, and should be fully involved in decisions about how and where palliative management takes place.

106. In **moderate to high risk** cases, the role of the consultation is critical in supporting parents and professionals to agree on the right pathway for their baby. Parents should be provided with as much information as is available, and should have the time (if possible) over a number of discussions to work through the different options available in order to agree with professionals what the right decision is for their family.

107. In **lower risk** cases, parents should be provided with relevant information about the risk to their baby, and the recommendation that it will be in the best interests of their baby to offer active treatment both antenatally and after birth. Parents should be told about likely interventions and what may happen next, and be fully involved in decisions about how active treatment is managed.

108. Thus, consultation is most critical where delivery would be associated with a **moderate to high** risk of unacceptably poor outcome (see main text). In such situations parents need support to make an informed choice about the provision of either active or palliative management; such situations demand the greatest care and sensitivity.

109. When is the right time?

110. Evidence suggests that parents find that, where time allows, consultation is most useful at the earliest opportunity, both to allow time for information processing, discussion, and decision making, and to minimise the effects of labour and medications on cognition. Follow up consultations allowing ongoing dialogue are highly valued by families^(51,52) and should be offered at any point, acknowledging the challenging nature of the information that parents are being asked to receive, the time this may take to process, and the decisions that need to be made.

111. Who should be involved?

112. Consultation with parents should ideally be provided by the most experienced members of the perinatal team involved in care of the mother and her baby. Continuity of care is essential and, whenever possible, consultation should be delivered as a joint obstetric, neonatal and midwifery approach, ensuring transparency and consistent, clear communication. The presence of members of the multidisciplinary team (particularly nurses and midwives) during such conversations is highly valued by families, and may provide opportunity for clarification and ongoing conversation outside the formality of such settings^(52,53). Parents may also find the advice and support of their family, friends, spiritual advisers and/or voluntary organisations to be of great value at this time.

113. Structuring the Consultation

114. **Exploring the parents' prior knowledge and understanding** can be a useful way to open the consultation, to establish what would be helpful for them in the conversation. This can explore the parents' own understanding about the risks of their situation, their prior experience and knowledge, and their expectations of the conversation. Parents' hopes, priorities and expectations of the care that they and their baby will receive should be explored with sensitivity, honesty and compassion in a realistic way.
115. **Balanced Information** - Studies suggest that conveying solely negative information to parents is not well received. Providing balanced information with honesty seems to be most useful to parents and respecting the importance of hope, even in the most difficult of situations, is highly valued. Exploring parental hopes, wishes and fears in each scenario can help to do this, and to build trust and rapport with the clinical team. Where survival is not possible, or is extremely unlikely, parental hopes relating to spending time with their baby, involving family members, and memory making should be explored.
116. **Conveying Risk** - Categorisation of risk to the baby of death or survival in a given scenario should be conveyed sympathetically but unambiguously. Parents may find it useful to see this displayed graphically. Gestation-based risk should be explained within the context of other risk modifiers (such as birth weight, gender, multiplicity, etc.). It is important to convey information accurately, in the appropriate context. For example, the most relevant statistic for parents is usually the chance of survival if active stabilisation and neonatal intensive care is attempted. Not all parents find percentage figures easy to understand. It can be helpful to explain in terms of odds e.g. 1 in 4, or 1 in 10. To avoid framing bias, we suggest interpreting risk neutrally. For example, *"Given what we know about the situation for your baby, there is a 30% chance of your baby surviving. This means that for every 10 babies treated actively (with intensive care) in situations like this, 3 would survive, while, sadly 7 would not"*.
117. **Discussing Poor Outcomes** - There is not a simple definition of a 'poor' outcome – the interpretation of this is likely to vary greatly between clinicians, parents, and families. Published data generally refer to scoring systems and classification of motor and cognitive dysfunction, but also often include children with profound vision or hearing loss. Some of these terms may not be meaningful to families, and families may differ in the outcome that they would regard as unacceptably poor. Therefore, discussions should include exploration of the parents' views and values relating to an acceptable outcome.
118. Conveying the concept of severe disability in childhood, and the possible implications for future quality of life, is difficult. Some helpful phrases may include:
- Not being able to walk, or mobilise independently
 - The possibility of being unable to communicate verbally
 - Difficulties with swallowing or feeding safely
 - The possibility of not being able to understand the world around them in a meaningful way
 - Not being able to see or hear properly
 - Being dependent on others for self care, and not being able to live independently
 - Having a lot of health care needs with frequent visits to hospital
 - Needing extra educational support (or needing to attend a special school)
119. **Discussing Palliative Care** – Where appropriate, the practicalities of commencing, withholding and withdrawing intensive care, and the positive role of palliative care should be described to the parents. This will help prepare them for possible outcomes after the birth. It can be useful to speak about memory making, and exploring parents' hopes and wishes. Please refer to guidance from Together for Short Lives and the National Bereavement Care Pathway.
120. <https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Perinatal-Pathway-for-Babies-With-Palliative-Care-Needs.pdf>
121. http://www.nbcpathway.org.uk/file/aw_5844_nbcpathway_neonatal_death_pathway.pdf

122. Decision making – A shared decision making process is vital, especially in situations of moderate-high risk of unacceptably poor outcome. Support and guidance should be tailored to the needs of each family.

123. Parental Involvement in Care - Evidence suggests parents find it very useful to hear how they can be involved in care for their baby. “Family-centred care means supporting parents to be involved in their baby's care”⁽⁵⁴⁾ – this should start before birth.

- a. Where it is planned to offer active care to the baby, and time allows, parents should be given an opportunity to visit the neonatal unit and to meet staff, and should receive information and support regarding expressing breast milk and the other ways that they could be involved in the hands-on care of their baby if s/he is admitted to the neonatal unit.

124. Documentation & Follow up - Communication and agreed plans must be documented in full in the clinical record and plans revised regularly if pregnancy continues, and/or depending upon the condition of the baby at birth and in the early days after birth. If *in utero* transfer is undertaken, the content and results of previous conversations must be clearly communicated (verbally, and in writing) with the receiving centre. Evidence suggests that parents find it very useful to receive supplemental information, such as written information, visual aids, and links to other resources. We include a suggested template for this information below.

126. Appendix 4: Helping parents to understand extreme preterm birth.

127. Who is this information for?

128. You have been given this information because your healthcare team think that you may have your baby extremely early (prematurely). You and your family need to know what is likely to happen for you and your baby if this occurs. The maternity team and neonatal (specialist baby doctors) team will talk to you about this in detail as well as giving you this information.

129. What does this mean?

130. A pregnancy usually lasts for about 40 weeks. How many weeks you are along in your pregnancy (gestation) is usually worked out from an ultrasound scan at around 12 weeks (your dating scan).

131. Babies born before 22 weeks are so small and fragile that they do not survive. Their lungs and other organs are not ready for them to live outside the womb. Such tiny babies may show signs of life for a short time after birth, but even with the very best neonatal care they cannot survive for more than a few minutes or hours.

132. Babies born from 22-26 weeks may be able to survive if they receive intensive medical treatment. However, some extremely premature babies sadly die despite this treatment.

133. Babies who are born extremely early are also at increased risk of problems with health and development as they grow up. These risks get higher the earlier (more prematurely) a baby is born, especially for those born before 25 weeks of gestation.

134. The doctors and midwives will talk to you about what they expect for your baby. In some situations, there are difficult decisions to be made about how to care for your baby before and after birth. The right thing to do can be different for different families. That is why it is important that you are fully informed, and able to let the doctors and midwives know your wishes for your baby.

Outcome of births between 22 and 26 weeks of gestation

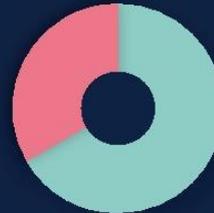
Survival ● Died ● Survived
In babies receiving active stabilisation

Severe disability ● Severe disability ● No severe disability**
In survivors**

Gestational week

22
weeks

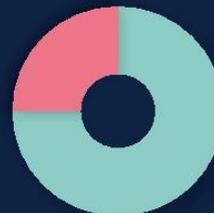
7 in 10 babies die
[51 to 79%]*
●●●●●●●●
3 in 10 babies survive



1 in 3 babies have severe disability
[24 to 43%]
2 in 3 do not**

23
weeks

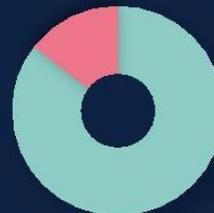
6 in 10 babies die
[56 to 68%]*
●●●●●●●●
4 in 10 babies survive



1 in 4 babies have severe disability
[16 to 33%]
3 in 4 do not**

24
weeks

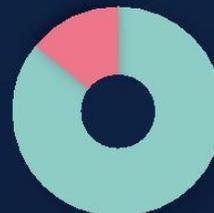
4 in 10 babies die
[35 to 45%]*
●●●●●●●●
6 in 10 babies survive



1 in 7 babies have severe disability
[11 to 24%]
6 in 7 do not**

25
weeks

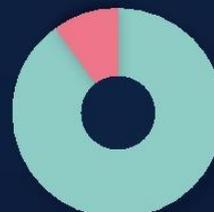
3 in 10 babies die
[22 to 30%]*
●●●●●●●●
7 in 10 babies survive



1 in 7 babies have severe disability
[10 to 21%]
6 in 7 do not**

26
weeks

2 in 10 babies die
[15 to 21%]*
●●●●●●●●
8 in 10 babies survive



1 in 10 babies have severe disability
[6 to 14%]
9 in 10 do not**

The survival percentages are for babies who are born alive and receive active stabilisation. Some extremely preterm babies do not survive labour.

* The lower and upper figures indicate how certain we are of the true survival rate.

** Up to a quarter of children without severe disability may nonetheless have other functional impairments such as learning difficulty, mild cerebral palsy or behavioural problems.

'Outcome'

135. These pictures are based on what we know about the small number of babies born extremely prematurely in the UK. They show how many babies survive out of every 10 babies born this early, and of those who do survive, how many are likely to have a 'severe disability' when they grow up.
136. The chance for your baby depends on a number of different things. As well as how early they are born, it also matters how much your baby weighs when it is born, whether it is a boy or girl, whether it is a multiple birth, and also how well you and your baby are around the time of birth.
137. **What does 'severe disability' mean?**
138. Disability can mean different things to different people. When talking about babies who have been born extremely prematurely, the term severe disability includes problems such as:
- Not being able to walk, or even get around independently (this includes conditions such as severe cerebral palsy)
 - Being unable to talk, or see or hear properly
 - Difficulties with swallowing or feeding safely
 - Having multiple health problems with frequent visits to hospital
 - Needing extra help at school
 - Being unable to care for themselves or live independently as they grow up
139. **What does this mean for your baby?**
140. We don't know exactly the future for your baby. Every baby is different, and it is important to talk with your doctors and midwife. They will give you specific information about your own and your baby's condition.
141. **What can parents do?**
142. What is right for your baby and your family is very individual to you. Your doctors will talk with you about your situation and seek to understand what is important for you and your family. They will support and guide you, and involve you in making decisions about treatment for your baby. Thinking about your hopes, your wishes, and your fears about your baby can help the team to support you in the best way possible.
143. **What may happen with my baby?**
144. **The birth**
145. Some babies who are born this early do not survive labour and delivery. If this happens your baby will be given to you to hold for as long as you would like. You will have the opportunity to spend as much time with them as you would like, and to make some memories with them.
146. **Intensive Care:** You and the team may decide that starting neonatal intensive care would be best for your baby. This will mean you will need some extra treatments before your baby is born. You will be given steroids to help their lungs and brain, and magnesium which also helps your baby's brain. You may need to be transferred to a specialist centre, ideally before you have your baby, but there may not be time to do this safely. The team will also talk to you about the treatment that will be given to your baby immediately after birth, and what may happen next depending on how your baby reacts to this treatment.
147. If you, and the team, decide that intensive care is best for your baby, you should be offered the opportunity to be shown around the neonatal unit (if there is time for this) as it may help to familiarise yourself with the neonatal unit and the people that work there before your baby is born. You can also talk to staff about expressing breast milk, as this makes such a difference for premature babies.

148. **Comfort Care:** You and the team may decide that it will be best to offer comfort care to your baby. This might be because there is an extremely high risk that your baby will not survive, or is likely to suffer from life-long disability even with the very best treatment. Comfort care is also known as palliative care and is special care for babies whose time is precious but short. It means providing treatments that will make their time as comfortable as possible. We will encourage you to be part of this care. Holding your baby close to you and talking to your baby will be very comforting for your baby.
149. More information is available from Together for Short Lives (see link)
- 150. What if my baby doesn't come now?**
151. If your baby does not come in the next few days their chances may improve. Ideally, they will stay in the womb for as long as possible (depending on the health of you and your baby).
152. If that happens there may be different options for you and your baby around the time of birth. That will depend on when your baby comes, and on other things that affect the baby's chances of responding to treatment. If this is the case, your healthcare team will continue the conversation with you about what has changed and what different options may be available, depending on when your baby is likely to be born, and you will be able to discuss and revise your agreed plans accordingly.
- 153. What might my baby look like?**
154. Babies born this early can weigh less than half a kilogram (1 small packet of sugar) and can look quite different to how we imagine a newborn baby. Their skin is shiny, and thin, and covered with fine hair. Sometimes babies can be quite bruised from the birth. If the baby has died before being born, they will usually be still. Occasionally, where babies have died very close to being born, they may make brief reflex movements that disappear very quickly.
155. If your baby is born alive, they may take a breath and make a small cry, or they may not breathe. Their eyes may not be able to open yet. The baby's colour is often purple or blue to start with.
- 156. Transfer to a different hospital**
157. Research shows that for babies born before 27 weeks of gestation it is best, whenever possible, to be born in a specialist maternity unit with a specialist Neonatal Intensive Care Unit (sometimes called a 'Level 3 NICU'). If a baby born before 27 weeks of gestation is born in a maternity unit (or at home) where there is not a specialist NICU, then we know that the baby will generally do better if moved to a specialist NICU after birth.
158. If your hospital does not have a specialist NICU, this may mean that you will be offered transfer to one of these centres before your baby is born. We understand that this can be a very anxious time, and that you may be moved quite some distance from home. It can be very difficult to predict which mothers will deliver early and so sometimes, mothers will be moved to another hospital but their babies may not be born early.
159. It may also be the case that you are considered too unwell, or too far on in labour to be safely moved to another hospital before your baby is born. When it is not possible to transfer you before the baby has been born, your baby may be transferred by a specialist Neonatal Transport Team after the birth. Your own health needs may mean you will be unable to travel immediately with your baby, but your local maternity team will do everything they can to move you to the same unit as your baby as soon as it is safe to do so.
160. We appreciate that moving to another hospital can be distressing for you and your family, especially if you

are separated from your baby for a while. We will talk to you about this in more detail if it is decided that this is the best option for your family.

161. What if I have more questions?

162. This information has been provided to you as part of the conversation that your healthcare team will have with you about your baby. If you have any other questions do make sure you ask your doctors and nurses to answer them, so you have all the information you need about your situation and the options available to you. Your healthcare team want to work with you to make the best decision, for your baby and for your family.

163. This space is for the health care team who are discussing this with you to write extra details about your baby or babies.

164. You may want to use this space to write down some questions to discuss with the team.

165. Many families find it useful to have follow-up discussions, so please ask to speak to the neonatal and maternity team again at any point.

166. Useful contact details:

167. Bliss - Premature and sick baby charity

<http://www.bliss.org.uk/>

Together for Short Lives - Charity for babies and children with life-limiting conditions

<https://www.togetherforshortlives.org.uk/>

Helpline: 0808 8088 100

Sands - Stillbirth and neonatal death charity

<https://www.uk-sands.org/>

Helpline: 0808 1643332

Email helpline@sands.org.uk

Appendix 5: Example scenarios

Case 1.

168. A mother has been admitted to a local maternity unit in preterm labour at 24⁺³ weeks of gestation. The singleton male fetus is very small with an estimated fetal weight of 450 grams. The family has another child born extremely preterm, who has severe cerebral palsy. The mother has not yet received antenatal steroids. The on-call paediatric team is asked to provide counselling and attend the birth.
169. As per the Framework, the first step is to assess the risk for the baby if delivery occurs. At a gestation of 24⁺³ weeks, the average survival rate for liveborn babies in the UK (if active treatment is provided) would be approximately 60%, with a 1 in 7 risk of severe impairment among survivors. However, in this case, the very low birth weight for the gestational age in a male fetus would increase the risk. It is difficult to quantify this risk, but the baby's prognosis is worse than average for 24 weeks of gestation, and within the "moderate to high" risk category.
170. Given the risk for the baby, counselling should, if possible, be provided by an experienced senior trainee or consultant neonatologist in conjunction with the obstetric team. If possible, this counselling should take place after the local team has discussed the case with the nearest NICU. It would be appropriate to provide active obstetric and neonatal management if that were desired by the parents. However, it would also be appropriate to provide palliative care, if that was felt by the parents to be in the baby's best interests.
171. In this case, the parents decide, after consultation, that they wish the baby to receive palliative care. Labour progresses, and a live-born baby is delivered weighing 460 grams. The paediatric team attend to support provision of palliative care. The baby is wrapped and given to his parents to hold. He dies at approximately 30 minutes of age.

Case 2.

172. A mother presents in preterm labour to a level 2 centre at 22⁺³ weeks of gestation. The fetus was conceived by IVF and gestation is certain. The fetus is female and has an estimated fetal weight of 480 grams. The mother has not yet received antenatal steroids. The paediatric team is asked to provide counselling and attend the birth.
173. Risk assessment in this case indicates that if birth occurs imminently, there would be an extremely high risk of the baby dying or of surviving with severe impairment. If labour progresses, it would be usual to provide palliative care at birth. The neonatal team may attend the birth to provide support for palliative care, but not to provide resuscitation.
174. However, there are potentially modifiable risk factors in this case. In the absence of evidence of chorioamnionitis, it may be possible to delay preterm birth with tocolysis and so, if the parents desire an active approach to management, antenatal transfer and corticosteroids could be provided.
175. Two days later, following transfer to a maternity unit co-located with NICU and administration of steroids, labour progresses. Given the advance in gestation, availability of specialised neonatal intensive care, and anticipated effect of corticosteroids, the baby's risk now falls in the "moderate to high" category. Accordingly, after further consultation with parents, it would be appropriate to provide active management if this is what parents wish.
176. In this case, the parents decide that they wish the baby to receive active neonatal care, magnesium sulphate is given, and a live baby is born weighing 490 grams. The baby is intubated, receives surfactant and is transferred to neonatal intensive care.

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