Extreme Preterm Pathway (document 1)
All Wales Standards

In October 2019 the British Association of Perinatal Medicine (BAPM) published a new framework for the perinatal management of extreme preterm birth before 27 weeks gestation. This supersedes previously published guidance by BAPM and the Nuffield Council of Bioethics (2006)[1] which were largely based on data from the original EPICure study (1995)[2,3] and preliminary data from EPICure 2. The new framework was developed by a multidisciplinary working group in the light of evolving evidence suggesting that outcomes for babies born before 27 completed weeks of gestation may be improving, and a national and international shift in the approach to their care.

The full document can be found be here:
https://hubble-live-assets.s3.amazonaws.com/bapm/attachment/file/182/Extreme_Preterm_28-11-19_FINAL.pdf

BAPM executive summary and visual risk tool:

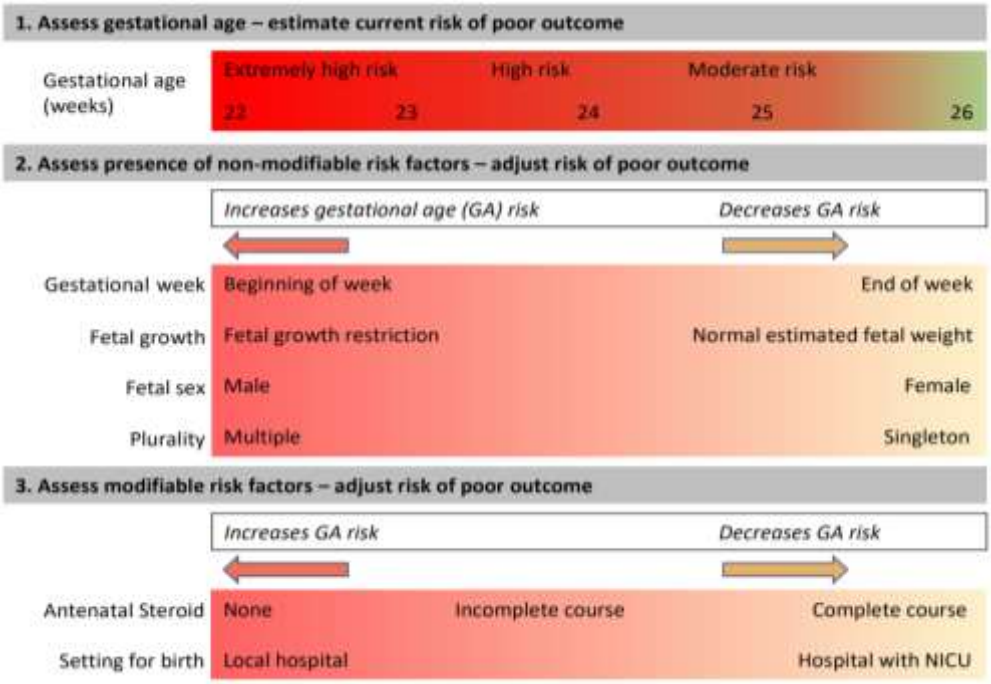
1. Management of labour, birth and the immediate neonatal period should reflect the wishes and values of the mother and her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals.

2. Whenever possible extreme preterm birth should be managed in a maternity facility co-located with a designated neonatal intensive care unit (NICU).

3. Neonatal stabilisation may be considered for babies born from 22^{+0} weeks of gestation following assessment of risk and multi-professional discussion with parents. It is not appropriate to attempt to resuscitate babies born before 22^{+0} weeks of gestation.

4. 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 referral centre if transfer is being contemplated.

5. Risk assessment should be performed with the aim of stratifying the risk of a poor outcome into three groups: extremely high risk, high risk, and moderate risk. The visual tool below may be used to guide the risk assessment and stratification.



6. For foetuses/babies at extremely high risk, palliative (comfort focused) care would be the usual management.

7. For foetuses/babies at high risk of poor outcome, the decision to provide either active (survival focused) management or palliative care should be based primarily on the wishes of the parents.

8. For foetuses/babies at moderate risk, active management should be planned.

9. 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 and subsequently.

10. Conversations with parents should be clearly documented and care taken to ensure that the agreed management plan is communicated between professionals and staff shifts.

11. Decisions and management should be regularly reviewed before and after birth in conjunction with the parents; plans may be reconsidered if the risk for the foetus/baby changes, or if parental wishes change.

Standards:

The aim of introducing standards in relation to the new framework is to support implementation of the framework and provision of equitable perinatal care for all extreme preterm births across Wales.

1. A multi-disciplinary team discussion involving at least one senior obstetrician and neonatologist/paediatrician should be held for all foetuses at risk of extreme preterm delivery between 22^{+0} and 26^{+6} weeks. For mothers presenting to a maternity facility without a co-located designated neonatal intensive care unit (NICU) advice may be sought from obstetric and/or neonatal professionals from the usual regional maternity centre with a co-located NICU.

2. The aim of the multi-disciplinary discussion is to jointly assess the risk of a poor outcome and stratify the perceived risk as either extremely high, high or moderate as per the BAPM framework. In addition to the non-modifiable risk factors highlighted in the BAPM visual risk tool, premature rupture of membranes with subsequent development of reduced or absent amniotic liquor volume should be considered as an important risk factor. The proposed risk category including the reasoning for such should be clearly documented.

3. A senior obstetrician and neonatologist/paediatrician should jointly counsel expectant parents regarding the risk to the foetus and proposed management in view of the perceived risk. The involvement of a tertiary neonatologist in parental counselling discussions should be considered for mothers presenting to maternity facilities without a co-located NICU.
   a. If possible, all discussions should take place with both parents (or alternative support person) present.
   b. The wishes and values of the parents should be sought and clearly documented.
   c. If time allows, at least two separate discussions should take place.

4. If palliative (comfort focused) care at delivery is agreed upon, the perinatal management should be aimed at optimising the comfort of the baby as well as offering support and choices to the parents.

   a. All discussions with parents regarding the delivery of palliative care should be carried out by senior staff.
   b. Measures aim at optimising the condition of the baby at birth such as maternal steroids and Magnesium Sulphate are not indicated.
   c. The neonatal team may be involved in the delivery of perinatal palliative care if the parents and obstetric staff feel this may be helpful.
   d. Parents should be made aware that their baby may be born alive and may live for a period of time.
   e. The parents' wishes regarding the care of their baby should be explored. This may include:

i. Holding the baby
ii. Memory making
iii. Blessing/Baptism
iv. An unofficial 'certificate of birth' for babies who were born dead before 24 weeks' gestation may be offered to parents. When a baby is born dead before 24 weeks' gestation (the current legal age of viability), the baby's birth cannot be legally registered or certified which some parents may find very distressing. A selection of templates of unofficial 'birth certificates' are freely available for download on the Sands website (https://shop-sands.org.uk/en/products/bereavement-support).
v. Pharmacological management of symptoms if required.

5. If survival focused management at delivery is agreed upon, the perinatal management should be aimed at optimising modifiable risk factors. This includes:
    a. Arrangement of in-utero transfer to a maternity facility with NICU if deemed safe by the obstetric team.
    b. Administration of maternal steroids without delay.
    c. Administration of maternal Magnesium Sulphate.
    d. Consideration of optimum mode of delivery.
    e. Optimisation of delivery room management:
        i. Experienced neonatal team present at delivery
        ii. Aim delivery room temperature above 25°C
        iii. Stabilisation as per NLS guidance.

6. Any agreed upon management plan needs to be reviewed regularly and may need to be revised if the initially proposed risk to the foetus changes and/or parents and professionals agree on an alternative management plan.

References:

1 Critical care decisions in fetal and neonatal medicine: ethical issues. Nuffield Council on Bioethics 2006 www.nuffieldbioethics.org

2 Costeloe K, Hennessy E, Gibson AT, Marlow N, Wilkinson AR, The EPICure study: Outcome to discharge from hospital for infants at the threshold of viability. Pediatrics 2000;106:659-671.

3 Marlow N, Wolke D, Bracewell M, Samara M, for the EPICure Study Group. Neurologic and developmental disability at 6 years of age after extremely preterm birth. N Engl J Med 2005; 352:9-19.