Appendix 1: EPICure 2 dataset [posted as supplied by author]

Items requiring an answer yes or no or not known are indicated y/n/nk, ranges of options are given in parentheses.

All births

Items 8-digit patient identifier.
Summary data submitted at 28days or death if sooner: case definition (late fetal loss, stillbirth, livebirth); timing of death for stillbirths and late fetal losses (antepartum, intrapartum, not known); legal abortion y/n/nk, outcome for livebirths (early death on labour ward, death <7d on NICU, death 7-27d, alive at 28d, not known)

Maternal items, pregnancy and delivery
Maternal date of birth, dd/mm/yy, or age if date of birth not known; Ethnic group (White, Black African, Black Caribbean, Black other, Indian, Pakistani, Bangladeshi, Chinese, mixed [specify], other [specify], not known); maternal height and weight, maternal BMI if available and weight and height not known; previous pregnancy outcomes: (spontaneous miscarriages, terminations of pregnancy, stillbirths, livebirths, caesarean sections, preterm births 24 – 36w); date of last menstrual period dd/mm/yyyy (certain, uncertain, not known); date of first booking appointment dd/mm/yyyy (certain, uncertain, not known, never booked); date of first scan dd/mm/yyyy or never scanned; gestational age at first scan ww+d; intended place of delivery at booking (hospital [specified], home, outside UK, not known); actual place of delivery (hospital [specified], outside hospital, not known); if hospital delivery (on labour ward, not on labour ward, not known); main reason for change between planned and actual place of delivery (no change, change of address during pregnancy, preterm labour and emergency admission to different hospital, planned in-utero transfer for clinical reasons, planned in-utero transfer for other reasons e.g. lack of capacity, not known); maternal smoking in pregnancy at time of booking (y/n/nk); maternal medical complications in pregnancy – indicate all that apply (none, pre-pregnancy diabetes type 1 or 2, gestational diabetes insulin dependent/non insulin dependent, essential hypertension on treatment at time of booking, epilepsy on treatment at first booking); obstetric complications – indicate all that apply (none, prolonged pprom >24h with date of membrane rupture dd/mm/yyyy, abruption, ante-partum bleeding after 20 completed weeks, pre-eclampsia, cervical suture); clinical suspicion of chorioamnionitis at any time before birth with date specified y/n/nk; maternal pyrexia >37.5^{O}C during 24h before birth yes with temperature specified/ no/ nk; chorioamnionitis noted at the time of birth y/n/nk; maternal antibiotics within 24h of birth (none, prophylaxis for PPROM, prophylaxis for known GBS carriage, treatment for suspected chorioamnionitis, treatment for other [specified], not known); evidence of fetal compromise >24h before birth (none, IUGR, oligohydramnios without PPROM); ante-partum CTG >24h before birth (none, normal, non-reassuring, pathological, not known); ante-partum Dopplers >24h before birth (not done, normal, evidence of redistribution with umbilical artery end diastolic flow present, umbilical artery absent or reversed end-diastolic flow, not known); ante-natal steroids (none, betamethasone, dexamethasone, not known + if given last dose more or less than 24h before birth, not known); tocolysis (none, atosiban, ritodrine, indometacin, nifedipine, other [specified]); labour (induced + main indication, spontaneous, spontaneous with augmentation, never in labour, not known); fetal monitoring in labour (none, continuous CTG, intermittent CTG, auscultation only, not known); CTG interpretation in labour (normal, non-reassuring, pathological, not known); epidural y/n/nk; presentation immediately prior to delivery (cephalic, breech, other, not known); mode of delivery – include all attempted – (spontaneous, instrumental,

caesarean section, not known); caesarean section indication if applicable – include all – (immediate threat to life of mother and/or fetus, maternal and/or fetal compromise not immediately life threatening); health professionals present immediately before birth – indicate all present – (none, qualified midwife, student midwife, consultant obstetrician, obstetric middle grade, obstetric SHO or F1/F2, ANNP, neonatal nurse, consultant paediatrician, paediatric middle grade, paediatric SHO or F1/F2); maternal supporters present during labour or delivery (none, partner, children, other family members, friends, lay supporter); fetus alive at admission to hospital: y/n/nk; fetus alive at onset of labour: y/n/nk; congenital anomaly suspected before birth (yes [specify], no, not known); congenital anomaly noted at delivery (none, present [specify], possible dysmorphism [specify], not known); was a plan for preterm birth discussed with an middle grade or consultant obstetrician (no opportunity, no, yes, not known); was a decision made not to perform a CS for fetal distress (y/n/nk); was paediatric counselling provided if so by whom (none, consultant, middle grade doctor, ANNP, SHO or F1/F2, nurse other than ANNP); did the parents express a choice about resuscitation and the provision of intensive care (no choice expressed, provide full intensive care for any live birth, withhold intensive care, assess and provide care at paediatric discretion, not known); was the possibility of withholding intensive care discussed (y/n/nk); date and time of birth.

Live births only

Trunk in occlusive wrapping at birth to avoid hypothermia y/n/nk; any heart rate at birth y/n/nk; signs of life in the first hour - indicate any that apply – (audible cry, spontaneous breathing, active body movements, heart beat); resuscitation – incluse any that apply – (not attempted, stimulation, oxygen, mask ventilation, ventilation via ETT + age at intubation, nCPAP, CPR, adrenaline, sodium bicarbonate); heart rate >100bpm at 5 minutes y/n/nk; surfactant given on labour ward y/n/nk

Babies admitted to Neonatal Unit for intensive care

If there was neither dating scan or certain LMP was the consultant confident that the GA was <27 weeks (y/n/nk); agreed gestational age at birth (ww/d); for what type of care was the baby admitted to the NNU (intensive, palliative, nk); name of hospital where baby was first admitted; date and time of admission; birth weight (n.nnn kg / never recorded); head circumference at birth (nn.n cm); sex (male, female, indeterminate); maximum base deficit in first hour (nn.n mm/l); maximum appropriate FiO_2 in first 12h (n.nn); minimum appropriate FiO_2 in first 12h (n.nn); maximum base deficit in first 12h (mm/l); temperature at admission (nn.n^{O}C); time temperature taken; surfactant given after admission to NNU (none, animal derived, synthetic, not known); prophylactic indometacin or ibuprofen (y/n/nk); transferred to another hospital within 24h of birth (no, yes – if yes where & time of admission to second hospital); TPN given (yes/no, if yes dates started amino acids and lipids) date enteral feed started (date / never fed); maternal breast milk at any time (y/n); date reached enteral feeding 150 ml/kg/day; any maternal breast milk at discharge (y/n/nk); at 36w pma still receiving mechanical respiratory support (yes/no); at 36w still receiving oxygen (no, ≥30% O_2, <30%O_2, low flow O_2 >0.1l/min, ≤0.1l/min); date last in supplemental O_2; home in O_2 (y/n); systemic steroid for BPD (none, dexamethasone, other [specify], date first given, starting dose mg/kg/day, weight when started, total days given steroid, number of separate courses, total dose mg); pulmonary haemorrhage (y/n); details of corticosteroid given other than for BPD; positive blood culture at first admission (none, GBS, E Coli, other [specify]; any other positive blood culture within 72h of birth (none, GBS, E Coli, other [specify]; positive blood culture >72h after birth (none, coagulase negative Staph, other{specify]); PDA treated with indometacin and/or ibuprofen (y/n/not applicable); ligation of PDA (y/n/not

applicable); were any suspected congenital anomalies confirmed (y/n/nk + details); were additional congenital anomalies detected & confirmed on NNU (y/n/nk); screened for ROP (y/n); date of first screen: worst stage of ROP in each eye (none, I, II, III, IV, V); plus disease (y/n); date of first treatment; method of treatment (laser/cryotherapy); cerebral ultrasound scan information requested if available – first scan, week 1, weeks 2-6, week 7-EDD, all scored on each side for haemorrhage (none, germinal layer, intraventricular), ventricular size (no dilatation, ventricular index ≤4mm over 97th centile, ventricular index >4mm over 97th centile), parenchymal injury (no evidence of injury, HPI echodense, HPI porencephalic cyst, PVL), extent of PVL if present (frontal, parietal, posterior)*; surgical procedures (none, abdominal drain for suspected perforation, Laparotomy for NEC, Laparotomy for perforation without NEC, intestinal resection, stoma, inguinal hernia repair, v-p shunt, Rickman reservoir, other[specify]); weight, OFC and length at 40w pma or discharge if sooner; transfers after 24h – dates and details of destination hospitals; did medical staff at any time recommend withdrawal of intensive care (y/n).

* The definition published in 1995 (1) of severe cerebral ultrasound scan abnormality was " showing unilateral or bilateral parenchymal cysts and/or hydrocephalus". Review of the 1995 database and analyses reveals this to be an error and scans showing echodense haemorrhagic parenchymal infarcts were included in that analysis as in 2006.

Late fetal losses and stillbirths

Date and time of death if known; gestation at which death confirmed; cause of IUD after admission (feticide, abruption, IUGR and hypoxia, other [specify], nk).

All post-admission deaths

Was intensive care electively withdrawn after discussion between family and staff (y/n); date, time and place of death; principal category of death (congenital anomaly [specify], pulmonary immaturity, RDS, IVH, RDS with IVH, RDS with infection, infection, NEC, late sequelae of ventilation, other [specify], not known).

All deaths

Post mortem examination (held or to be held, not offered, permission refused, coroner's PM, consent given but not performed, not known).

Babies discharged from hospital

Date of discharge; need for interpretation (y/n), parents' names and address, name and address of GP.

Reference

1. Costeloe K, Hennessy E, Gibson AT, Marlow N, Wilkinson AR. The EPICure study: outcomes to discharge he EPICure study: outcomes to discharge from hospital for infants born at the threshold of viability. Pediatrics. 2000; **106**(4): 659-71.