Neonatal Intensive Care Units’ (NICUS) Data Collection – Variable checklist

The variables listed below are available subject to data custodian and ethical approval. Please indicate the variables requested and provide justification for their inclusion in your study. Note that identifying variables (e.g. name, address) have been displayed here but will not usually be released.

|  | Variable | Justification |
| --- | --- | --- |
|  | **Infant details** |  |
|  | Infant name | Not available to researchers |
|  | Infant date/time of birth |  |
|  | Birth hospital medical record number | Not available to researchers |
|  | NICUS registration hospital | Not available to researchers |
|  | NICUS registration hospital medical record number | Not available to researchers |
|  | NICUS random number |  |
|  |  |  |
|  | **Father details** |  |
|  | Name if available | Not available to researchers |
|  |  |  |
|  | **Mother details** |  |
|  | Name | Not available to researchers |
|  | Date of birth (from 2007 onwards) | Not available to researchers |
|  | Age |  |
|  | Address at baby’s birth (street number, street name, locality, postcode) | Not available to researchers |
|  | Local Health District of residence |  |
|  | Hospital of delivery | Not available to researchers |
|  | Medical record number at hospital of delivery | Not available to researchers |
|  | Ethnicity |  |
|  | Consanguinity (2010 onwards) |  |
|  |  |  |
|  | **Previous Pregnancies** |  |
|  | Total number |  |
|  | Number >20weeks gestation |  |
|  | Perinatal loss |  |
|  | Preterm birth |  |
|  |  |  |
|  | **Pregnancy Details** |  |
|  | Estimated date of delivery (2007 onwards) |  |
|  | Artificial reproductive techniques |  |
|  | Prenatal care (2007 onwards) |  |
|  | Duration of rupture of membranes |  |
|  | Date/time rupture of membranes (2006 onwards) |  |
|  | Antenatal steroids |  |
|  |  |  |
|  | **Pre-existing maternal medical problems (2003 onwards)** |  |
|  | Essential hypertension |  |
|  | Diabetes mellitus |  |
|  | Systemic lupus erythematosus |  |
|  | Chronic renal disease |  |
|  | Chronic cardiac disease (2007 onwards) |  |
|  | Other maternal medical problem |  |
|  |  |  |
|  | **Antenatal Complications** |  |
|  | Twin to twin transfusion (2007 onwards) |  |
|  | Hypertension of pregnancy |  |
|  | Gestational diabetes (2001 onwards) |  |
|  | Antepartum haemorrhage |  |
|  | Suspected intrauterine growth restriction by ultrasound |  |
|  | Antenatal diagnosis of fetal anomaly |  |
|  | Fetal compromise |  |
|  | Chorioamnionitis (2001 onwards) |  |
|  | Maternal antibiotics (2006 onwards) |  |
|  | Magnesium sulphate (2009 onwards) |  |
|  | Preterm labour |  |
|  | Drug use (2001 onwards) |  |
|  | Other antenatal complications |  |
|  |  |  |
|  | **Labour & Delivery details** |  |
|  | Presentation before delivery |  |
|  | Type of labour |  |
|  | Problem leading to delivery |  |
|  | Type of delivery |  |
|  |  |  |
|  | **Resuscitation details** |  |
|  | Oxygen |  |
|  | Mask/NPT |  |
|  | ETT ventilation |  |
|  | Adrenaline (2007 onwards) |  |
|  | Compressions (2007 onwards) |  |
|  | Tracheal suctioning for meconium (2007 onwards) |  |
|  |  |  |
|  | **Neonatal details** |  |
|  | Gestation |  |
|  | Birth weight |  |
|  | Birth weight percentile |  |
|  | Head circumference |  |
|  | Head circumference percentile |  |
|  | Sex |  |
|  | Plurality |  |
|  | Birth order |  |
|  | Place of birth |  |
|  | APGAR scores at 1 and 5 minutes |  |
|  | Admission temperature |  |
|  | Worst base excess/deficit in first 12 hours of life |  |
|  |  |  |
|  | **Morbidities** |  |
|  | Congenital anomalies – ICD-10-AM codes |  |
|  | Chronic lung disease (CLD) – respiratory support at 36 weeks for infants born <32 weeks gestation |  |
|  | Necrotising enterocolitis |  |
|  | Retinopathy of prematurity (ROP) |  |
|  | Intraventricular haemorrhage |  |
|  | Acquired hydrocephalus |  |
|  | Porencephalic cyst |  |
|  | Periventricular leucomalacia |  |
|  | Patent ductus arteriosus (PDA) |  |
|  | Spontaneous airleak |  |
|  | Seizures (2003 onwards) |  |
|  | Hypoxic ischaemic encephalopathy (2003 onwards) |  |
|  | Pulmonary hypertension (2003 onwards) |  |
|  |  |  |
|  | **Respiratory support details** |  |
|  | Primary respiratory diagnosis |  |
|  | High frequency ventilation (days) |  |
|  | CPAP (days) |  |
|  | High Flow oxygen/air >1/L (days) (2009 onwards) |  |
|  | Oxygen (days) |  |
|  |  |  |
|  | **Treatment details** |  |
|  | Surfactant |  |
|  | Nitric oxide |  |
|  | Inotropes (2010 onwards) |  |
|  | Antibiotics (2007 onwards) |  |
|  | Caffeine (2012 onwards) |  |
|  | Postnatal steroids for CLD |  |
|  | VegF intraocular injection for ROP (2012 onwards) |  |
|  | Indomethacin for PDA |  |
|  | Ibuprofen for PDA |  |
|  | Total parenteral nutrition |  |
|  | Immunisation (2007 onwards) |  |
|  | Intentional hypothermia (2007 onwards) |  |
|  | Blood transfusion (2007 onwards) |  |
|  | Exchange transfusion (2007 onwards) |  |
|  | Maximum serum bilirubin (2012 onwards) |  |
|  |  |  |
|  | **Sepsis details** |  |
|  | Blood and cerebrospinal fluid only |  |
|  | Date culture taken |  |
|  | Site |  |
|  | Organism |  |
|  |  |  |
|  | **Central line details (2003 onwards)** |  |
|  | Date in/out |  |
|  | Type of line |  |
|  |  |  |
|  | **Surgery details** |  |
|  | ICD-10-AM codes |  |
|  | Date surgery |  |
|  | Place surgery |  |
|  |  |  |
|  | **Feeding details (2003 onwards)** |  |
|  | Mother intended to breast feed |  |
|  | First feed breast milk |  |
|  | Discharge feed breast milk |  |
|  | Home on tube feeds (2007 onwards) |  |
|  |  |  |
|  | **Discharge details** |  |
|  | Age (days) at discharge |  |
|  | Growth parameters at discharge (from 2007 onwards) |  |
|  | SWISH Hearing test (2009 onwards) |  |
|  |  |  |
|  | **Death details** |  |
|  | Date/time of death |  |
|  | Death prior to discharge |  |
|  | Place of death |  |
|  | Cause of death |  |
|  | Postmortem performed |  |
|  |  |  |
|  | **Developmental outcome at 1 and 2-3 years of age, corrected for prematurity for infants <29 weeks gestation born 1/1/1998 onwards** |  |
|  | Weight |  |
|  | Height |  |
|  | Head circumference |  |
|  | Cerebral palsy |  |
|  | Bilateral blindness |  |
|  | Bilateral hearing aids |  |
|  | Unilateral/bilateral cochlear implants |  |
|  | Developmental delay |  |
|  | Functional disability |  |

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| --- |
| Other/comments |
|  |