

Brain injury occurring during or soon after birth: a report for the national maternity ambition commissioned by the Department of Health

Authors: Dr Chris Gale, Mr Eugene Stanikov, Ms Sena Jawad, Dr Sabita Uthaya, Professor Neena Modi

Affiliation: Neonatal Data Analysis Unit, Imperial College London, Chelsea and Westminster Hospital campus, SW10 9NH

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1 Context

In November 2015, the Secretary of State for Health announced a national ambition to halve the annual rates of stillbirth, neonatal death, maternal death and brain injuries occurring during or soon after birth in England, by 2030, with a reduction of 20% by 2020.¹ The baseline or reference year, against which the rate in 2020 and 2030 will be compared, is 2010.

The Department of Health commissioned the Neonatal Data Analysis Unit (NDAU) at Imperial College London to extract data from the National Neonatal Research Database (NNRD) and to calculate annual rates for *Brain injuries occurring during or soon after birth* for England from 2010 to 2015.

In this report we describe a working definition that has been agreed for *Brain injuries occurring during or soon after birth*, the data items that make up this definition, the methodology used and annual rates for 2010-2015 for England.

¹ <https://www.gov.uk/government/news/new-ambition-to-halve-rate-of-stillbirths-and-infant-deaths>

2 Defining *brain injuries occurring during or soon after birth*

Brain injuries occurring during or soon after birth does not have an agreed or standardised definition; in view of this, an expert group was convened by the Department of Health to determine a working definition for the national maternity ambition.

The meeting was convened on 12th January 2017, at Richmond House, London and chaired by Mr Matthew Jolly, National Clinical Director for Maternity Review and Women's Health. Attendees and their affiliations are provided in Appendix 1. A briefing paper was circulated in advance of the meeting, Appendix 2. A report of the meeting is provided in Appendix 3.

The expert group agreed the following criteria for *brain injuries occurring during or soon after birth* for the national maternity ambition:

- **Population: *all babies admitted to a neonatal unit***
- **Time period after birth: *all brain injuries that are detected during the neonatal unit stay***
- **Conditions to be included:**
 - a. *Infants with signs consistent with **neonatal encephalopathy** (altered tone, altered consciousness, seizures): term and near term infants only*
 - b. *Infants with a diagnosis of **intracranial haemorrhage, perinatal stroke, hypoxic ischaemic encephalopathy (HIE), central nervous system infection, and kernicterus (bilirubin encephalopathy)**: all infants*
 - c. ***preterm white matter disease (periventricular leukomalacia)**: preterm infants only*
- **Denominator: *all live births* to be used as the denominator for calculating the annual rate of "brain injuries occurring during or soon after birth"**
- **Exclusions:** a consensus decision was made to present data before and after exclusion of infants with the following conditions: ***congenital encephalopathies (including inborn errors of metabolism), congenital infections and congenital brain abnormalities***

The NNRD data fields to be used to determine *brain injuries occurring during or soon after birth* are shown in Appendix 4.

3 Data sources

3.1 National Neonatal Research Database

The principal data source commissioned by the Department of Health for the calculation of annual rates of *brain injuries occurring during or soon after birth* for the national maternity ambition is the National Neonatal Research Database (NNRD).

In the United Kingdom summary electronic patient data are entered on all admissions to National Health Service (NHS) neonatal units in England, Wales and Scotland. These data are held in a national resource, the NNRD. Data in the NNRD have undergone detailed cleaning to identify duplicates, out of range values, internal inconsistencies, and other potentially erroneous entries. In addition to these internal processes, feedback quality assurance checks are undertaken with clinicians for key items. Data in the NNRD are merged across often multiple patient episodes to create a single record for each infant.

All neonatal units (currently 100% of neonatal units in England, Wales and Scotland) that contribute data to the NNRD form the UK Neonatal Collaborative, UKNC. Approximately 400 predefined data items, the Neonatal Data Set², are extracted quarterly from these electronic patient records to form the NNRD. The Neonatal Data Set is an approved NHS Information Standard.

All members of the UKNC were informed by the Department of Health on 12th January 2017 (Appendix 5) that data from neonatal units in England, held in the NNRD, will be used to calculate annual rates for *brain injuries occurring during or soon after birth*.

3.2 Denominator data source

The denominator is total live births in England, and was extracted from the Office for National Statistics (ONS) Birth Summary Tables - England and Wales³, accessed 20th February 2017.

²http://www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/national_neonatal_data_set/national_neonatal_data_set_-_episodic_and_daily_care_fr.asp?shownav=0

³ Office for National Statistics, accessed 21st February 2017, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsummarytables>

4 Methodology for calculation of annual rates of *brain injuries occurring during or soon after birth*

4.1 Calculating 2010 baseline

The NNRD holds data from approximately 90% of English NHS neonatal units from 2010 and 100% of English NHS neonatal units from 2012.

In 2010 there were 170 neonatal units in England. In January 2010 146 neonatal units contributed data to the NNRD, rising to 169 neonatal units by January 2011. A month by month breakdown of contributing neonatal units for 2010 and 2011 is provided in Appendix 6. All neonatal units in England contributed data on all neonatal unit admissions to the NNRD from January 2012 onwards.

The number of infants admitted to neonatal units that did not contribute to the NNRD, and the number of total live births in associated maternity units, in 2010 and 2011 were unknown. Admissions were estimated using yearly admissions from 2012 to 2015. There was an upward trend in the number of neonatal unit admissions from 2012 to 2015, suggesting that the admissions in 2010 and 2011 would have been lower than the later years and fitting an upward trend.

We estimated lower and upper margins for increases in the number of admissions based on the smallest and largest yearly increase seen in 2012 to 2015, assuming that the admissions in 2010 and 2011 will be as or less extreme than these. We estimated the standard deviation of the proportion of brain injuries to admissions using actual data from the NNRD and inflated the number of brain injuries on the lower increase in admissions by two standard deviations less than the actual brain injury rate for the lower estimate, and inflated by an increase in two standard deviations more than the actual brain injury for the upper estimate.

This method gave more of an overestimate for the upper estimate than the lower estimate. The new inflated rates were then calculated by taking the lower and higher estimates of brain injuries as a proportion of the total number of live births.

5 Results

5.1 Data

After extraction it was apparent that the data for *term and near term infants with signs consistent with neonatal encephalopathy (altered tone, altered consciousness, seizures)* were not consistent over time; interrogation of the dataset indicated that the fields used to define *altered tone* and *altered consciousness* only began to be used from October 2010 onwards. To ensure consistency between 2010 data and subsequent years the condition “*term and near term infants with signs consistent with neonatal encephalopathy*” was dropped and the condition “*seizures*” was included for preterm and term infants. The final data items used for the definition of *brain injuries occurring at or soon after birth* are presented in Appendix 7.

5.2 Brain injuries

Table 1: The number of infants in England (all gestational ages) with a diagnosis of *brain injury*, defined as shown in Appendix 7; data for 2010 and 2011 are adjusted to account for the incomplete coverage of the NNRD during those years as described on page 4 of this report, from 2012 onwards the NNRD has complete population coverage of neonatal admissions in England so no adjustment was necessary.

Year	Infants recorded in the NNRD	Infants with brain injury	Infants with brain injury adjusted for incomplete NNRD coverage	Live births in England	Rate of brain injuries per 1000 live births
2010	64,375	3,011	3,160 to 3,619	687,007 ⁴	4.60 to 5.27
2011	72,678	3,377	3,434 to 3,630	688,120 ⁵	4.99 to 5.28
2012	78,952	3,404	3,404 (not adjusted)	694,241 ⁶	4.90
2013	80,199	3,393	3,393 (not adjusted)	664,517 ⁷	5.11
2014	84,981	3,558	3,558 (not adjusted)	661,496 ⁸	5.38
2015	88,785	3,445	3,445 (not adjusted)	664,399 ⁹	5.19

⁴ Office for National Statistics, Birth Summary Tables, England and Wales 2010

⁵ Office for National Statistics, Birth Summary Tables, England and Wales 2011 (Final)

⁶ Office for National Statistics, Birth Summary Tables, England and Wales 2012 (Final)

⁷ Office for National Statistics, Birth Summary Tables, England and Wales 2013 (Final)

⁸ Office for National Statistics, Birth Summary Tables, England and Wales 2014

⁹ Office for National Statistics, Birth Summary Tables, England and Wales 2015

5.3 Brain injuries after exclusions

Table 2: The number of infants in England (all gestational ages) with a diagnosis of *brain injury*, before and after exclusions (as shown in Appendix 7); data for 2010 and 2011 are adjusted for incomplete coverage of the NNRD during these years.

Year	Infants recorded in the NNRD	Infants with brain injury (before exclusions)	Exclusions	Infants with brain injury (after exclusions)	Infants with brain injury adjusted for incomplete NNRD coverage (after exclusions)	Live births in England	Brain injuries per 1000 live births (after exclusions)
2010	64,375	3,011	45	2,966	3,113 to 3,566	687,007 ¹⁰	4.53 to 5.19
2011	72,678	3,377	46	3,331	3,387 to 3,581	688,120 ¹¹	4.93 to 5.20
2012	78,952	3,404	45	3,359	3,359 (not adjusted)	694,241 ¹²	4.84
2013	80,199	3,393	35	3,358	3,358 (not adjusted)	664,517 ¹³	5.05
2014	84,981	3,558	30	3,528	3,528 (not adjusted)	661,496 ¹⁴	5.33
2015	88,785	3,445	27	3,418	3,418 (not adjusted)	664,399 ¹⁵	5.14

¹⁰ Office for National Statistics, Birth Summary Tables, England and Wales 2010

¹¹ Office for National Statistics, Birth Summary Tables, England and Wales 2011 (Final)

¹² Office for National Statistics, Birth Summary Tables, England and Wales 2012 (Final)

¹³ Office for National Statistics, Birth Summary Tables, England and Wales 2013 (Final)

¹⁴ Office for National Statistics, Birth Summary Tables, England and Wales 2014

¹⁵ Office for National Statistics, Birth Summary Tables, England and Wales 2015

5.4 Term brain injuries

Table 3: The number of term (≥ 37 gestational weeks) infants in England with a diagnosis of *brain injury*, before and after exclusions (defined as shown in Appendix 7); data for 2010 and 2011 are adjusted to account for the incomplete coverage of the NNRD during these years; annual rates are not calculated for 2015 as gestational age specific annual live birth data for England for 2015 are not available.

Year	Term infants recorded in the NNRD	Term infants with brain injury	Term infants with brain injury adjusted for incomplete NNRD coverage	Term infants with brain injury after adjustment and exclusions	Term live births in England	Rate of brain injuries (per 1000 term live births) after exclusions
2010	35,415	1,830	1979 to 2218	1,949 to 2,186	627,357 ¹⁶	3.11 to 3.48
2011	41,429	2,126	2,213 to 2,285	2,179 to 2,249	630,419 ¹⁶	3.46 to 3.57
2012	46,200	2,109	2,109 (not adjusted)	2,074	640,787 ¹⁶	3.24
2013	47,935	2,130	2,130 (not adjusted)	2,105	612,816 ¹⁷	3.43
2014	51,945	2,215	2,215 (not adjusted)	2,189	607,972 ¹⁷	3.60
2015	55,045	2,136	2,136 (not adjusted)	2,116	-	-

¹⁶ Office for National Statistics, Births and Deaths by Gestation in England 2006-2011

¹⁷ Office for National Statistics, Tables on births and infant deaths by gestation, England only

5.5 Preterm brain injury (<37 gestational weeks)

Table 4: The number of preterm (<37 gestational weeks) infants in England with a diagnosis of *brain injury*, before and after exclusions (defined as shown in Appendix 7); data for 2010 and 2011 are adjusted to account for the incomplete coverage of the NNRD during these years; annual rates are not calculated for 2015 as gestational age specific annual live birth data for England for 2015 are not available.

Year	Preterm infants recorded in the NNRD	Preterm infants with brain injury	Preterm infants with brain injury adjusted for incomplete NNRD coverage	Preterm infants with brain injury after adjustment and exclusions	Preterm live births in England	Rate of brain injuries (per 1000 preterm live births) after exclusions
2010	28,960	1,181	1,273 to 1,310	1,254 to 1,290	43,928 ¹⁸	28.54 to 29.37
2011	31,249	1,251	1,281 to 1,298	1,268 to 1,284	44,547 ¹⁸	28.47 to 28.83
2012	32,752	1,295	1,295 (not adjusted)	1,285	49,949 ¹⁸	25.73
2013	32,264	1,263	1,263 (not adjusted)	1,253	48,844 ¹⁹	25.65
2014	33,036	1,343	1,343 (not adjusted)	1,339	49,379 ¹⁹	27.12
2015	33,740	1,309	1,309 (not adjusted)	1,302	-	-

¹⁸ Office for National Statistics, Births and Deaths by Gestation in England 2006-2011

¹⁹ Office for National Statistics, Tables on births and infant deaths by gestation, England only

Appendix 1

Brain injury expert group meeting attendees

Attendees

<i>Name</i>	<i>Organisation</i>
Professor Neena Modi	Imperial College London
Dr Chris Gale	Imperial College London
Eugene Statnikov	Imperial College London
Dr Sabita Uthaya	Imperial College London
Richard Colquhoun	Imperial College London
Nilum Patel	Department of Health
Sarah Hegarty	Department of Health
Madeline Percival	Department of Health
Hayley Butcher	Department of Health
Karen Todd	Department of Health
Emily Weston	Department of Health
Siobhain McKeigue	Department of Health
Dr Matthew Jolly	NHS England
James Wallis	NHS England
James Walker	Care Quality Commission
Tony Kelly	Kent, Surrey, Sussex Academic Health Sciences Network
Michelle Upton	NHS Improvement
Birte Harlev-Lam	NHS Improvement
Katherine Robbins	NHS Digital
Professor Marian Knight	National Perinatal Epidemiology Unit, Oxford
Dr David Odd	Senior Clinical Lecturer, University of Bristol
Dr Dimitrios Siassakos	Consultant Senior Lecturer, University of Bristol
Dr Michael Magro	Darzi Fellow, NHS Litigation Authority
Professor Nikki Robertson	Professor of Translational Neonatal Medicine, UCL
Professor Alan Cameron	RCOG Vice President, Clinical Quality
Professor Donald Peebles	Chair of Maternal Fetal Medicine, UCL
Dr Karen Luyt	Consultant Senior Lecturer, University of Bristol
Dr Paul Clarke	Consultant Neonatologist, Norfolk and Norwich Hospital

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Mandy Forrester	My Birthplace® project midwife
Julie Frohlich	Consultant midwife, Guy's and St Thomas' Hospital
Emily Petch	Royal College of Obstetrics and Gynaecology Each Baby Counts
Jacqui Dopran	Senior Neonatal Nurse, Homerton Hospital

The following were unable to attend and provided written responses:

<i>Name</i>	<i>Organisation</i>
Dr Topun Austin	Consultant Neonatologist, University of Cambridge
Dr James Boardman	Reader and Honorary consultant in Neonatal Medicine, University of Edinburgh
Dr Frances Cowan	Imperial College London

Apologies were received from the following:

<i>Name</i>	<i>Organisation</i>
Hannah Knight	Royal College of Obstetrics and Gynaecology
Jenny Kurinczuk	National Perinatal Epidemiology Unit, Oxford
Tim Draycott	University of Bristol
Professor Frances Cowan	Imperial College London
Professor Neil Marlow	Professor of Neonatal Medicine UCL Institute for Women's Health
Professor Marianne Thoresen	Professor of Neonatal Neuroscience, University of Bristol
Professor Helen Budge	Professor of Neonatal Medicine, University of Nottingham

Appendix 2

Appendix 2

Brain injury expert group meeting briefing paper

Context

In November 2015, the Secretary of State for health announced a national ambition to halve the rates of stillbirth, neonatal death, maternal death and the number of brain injuries occurring during or soon after birth by 2030, with a reduction of 20% by 2020.²⁰

Neonatal death, maternal death and stillbirth have standardised and agreed definitions with national annual statistics. *Brain injuries occurring during or soon after birth* however, does not have an agreed or standardised definition. The intention of this expert group meeting is to determine a working definition of '*brain injuries occurring during or soon after birth*' for the national maternity ambition.

This definition will be used as follows:

1. To set a baseline year for *brain injuries occurring during or soon after birth*;
2. To calculate annual rates of *brain injuries occurring during or soon after birth* from the baseline year and these data will be publicly available at national level;
3. To calculate annual and quarterly rates at neonatal network/maternity system level for units/networks/maternity systems to use to guide improvement in care.

Purpose

To agree a working definition for *brain injuries occurring during or soon after birth* that can be collected using existing data collection systems, to drive improvements in care delivery and for the purposes of tracking progress against the national maternity ambition.

This will involve:

1. Agreeing conditions to be included in the definition of *brain injuries occurring during or soon after birth*;
2. Agreeing the data items and data sources to be used to identify the conditions making up *brain injuries occurring during or soon after birth*.

²⁰ <https://www.gov.uk/government/news/new-ambition-to-halve-rate-of-stillbirths-and-infant-deaths>

Appendix 2

Background

Brain injury occurring at or around the time of birth can be secondary to a range of conditions, outlined in the following section.

Brain injury may be difficult to identify in the neonatal period, and the timing of injury may also be difficult to determine. Some markers of brain injury, and examples of the complexity inherent in identifying them are summarised below:

- Neonatal seizures, which occur in approximately 1-3 per 1000 term infants and 5-13% of very-low-birthweight infants (and are probably underreported) are seen in infants with hypoxic-ischaemic encephalopathy (a cause of *brain injury occurring during or soon after birth*) but are also seen in infants with congenital brain abnormalities (which are not a cause of *brain injury occurring during or soon after birth*).
- Hypoglycaemia (where a baby's blood glucose level is not sufficient to provide energy to the brain) may cause *brain injury occurring soon after birth*, but this may not be detected in the neonatal period, only becoming apparent several years later when a child is diagnosed with cerebral palsy.
- Severe jaundice, when detected in the neonatal period, will be treated to prevent kernicterus, a cause of *brain injury occurring soon after birth* - for example with an exchange transfusion (where an infant's blood is replaced in increments to reduce the high bilirubin level). It may not, however, be possible to determine whether the treatment successfully prevented brain injury until several months later.

It is because of these complexities that this expert group has been convened to agree a working definition.

Appendix 2

Conditions leading to brain injury that occur during or soon after birth

The following section outlines the major conditions that occur during or soon after birth and may lead to brain injury. We have tried to provide approximate annual numbers for England and Wales for each condition and some indication of the timing of injury where possible.²¹ Best estimates indicate that the conditions outlined below affect between 2500-4200 infants in England and Wales annually.

To put the incidence figures below into context, Office for National Statistics data for births in 2015 for England and Wales are:

- 697,797 live births
- 639,960 live births at 37 weeks or above (term birth)
- 53,209 live births below 37 weeks (preterm birth)
- 3,973 live births below 29 weeks (extremely preterm birth)
- 7,286 live births with a birthweight <1500g (very low birth weight, VLBW infants)

Hypoxic ischaemic encephalopathy (HIE): Hypoxic ischaemic brain injury is defined as diminished blood oxygen and blood perfusion of the brain. Encephalopathy is the clinical manifestation of disordered brain function in the newborn. The disorder is termed Hypoxic Ischaemic Encephalopathy (HIE) when there is evidence of intrapartum asphyxia as a cause of neonatal encephalopathy. The incidence of HIE has been estimated to be 1.5 per 1000 live births (~1000 annually in England and Wales). The timing of HIE is at birth with ongoing damage observed over the next few days.

Perinatal stroke: Perinatal stroke is damage to brain tissue from disruption of blood flow to the brain. It can occur secondary to blockage of the arteries (perinatal arterial ischaemic stroke) or blockage of the veins (cerebral venous thrombosis). Ischaemic stroke is common in the perinatal period estimated incidence of 1 in 2300-5000 (~140-300 cases annually in England and Wales). Cerebral venous thrombosis has an estimated incidence of 2.6 per 100,000 (~18 cases annually in England and Wales). Presentation is usually in the first 3 days after birth.

Intracranial haemorrhage in term infants: Intracranial haemorrhage refers to bleeding within or around the brain, it includes bleeds outside the brain, such as subdural, extradural or subarachnoid bleeds (bleeding that occurs within the layers surrounding the brain and may damage the brain); and bleeds within the brain itself such as intraventricular (bleeding into the ventricles within the brain) and intraparenchymal bleeds (bleeding into the brain tissue itself).

²¹ Data are taken largely from Rennie & Robertson's Textbook of Neonatology, 5th Edition, 2012, Ed. Rennie JM.

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The incidence of symptomatic intracranial haemorrhage in term infants has been estimated to be about 3/10,000 births (~190 cases annually in England and Wales). Presentation is usually in the first 2 days after birth.

Intracranial haemorrhage in preterm infants: This includes bleeding within or around the brain as in term infants, but among preterm infants bleeding predominantly occurs within the ventricular system.

Incidence has been estimated at between 20-30% of VLBW infants (1500-2200 cases annually), with incidence of more severe forms (intraventricular haemorrhage with ventricular dilatation or parenchymal damage) estimated at 10% of VLBW infants (~700 infants annually in England and Wales). The timing of this condition can be antenatal, peripartum or postnatal, with the majority occurring after birth within the first 72 hours. Only 10% occur beyond the first week after birth.

White matter disease of prematurity: This includes all damage to the white matter in preterm infants, recognising that the aetiology is not always clear. Included within this are cystic periventricular leukomalacia (PVL), diffuse white matter abnormalities and damage to the brain parenchyma associated with intraventricular haemorrhage.

Cystic PVL is estimated to have an incidence of 5% among infants born at <27 weeks gestation (~130 infants annually in England and Wales).

Timing of cystic PVL is much more variable than intraventricular haemorrhage in preterm infants and can be antenatal, peripartum or postnatal. There is a time lag between the causative brain insult and the appearance of cystic PVL on imaging (median time lag 10-39 days).

Central nervous system infections: This includes meningitis and encephalitis, and includes bacterial and other organisms (such as viruses and fungi).

The incidence of early onset (within the first 48 hours) meningitis, bacterial and other organisms, is 0.39 per 1000 live births (~270 cases annually in England and Wales). Herpes virus infection is the commonest non-bacterial cause of central nervous system infection with an estimated incidence of 1 in 50,000 live births (~14 cases annually in England in Wales).

Kernicterus: This refers to characteristic yellow staining of the brainstem seen in infants with acute bilirubin toxicity.

The incidence of acute bilirubin toxicity has been estimated to be 0.9 per 100,000 live births (~6 infants annually in England and Wales).

The incidence of severe hyperbilirubinaemia (likely to receive double volume exchange transfusion is estimated to be 7.1 per 100,000 (~50 infants annually in England and Wales).

The timing of acute bilirubin toxicity is dependent on the underlying cause, within the first 72 hours for infants with acute haemolysis and between days 4-10 among infants with other causes.

Hypoglycaemia: Hypoglycaemia is common and controversial in the newborn period. Hypoglycaemia can lead to neonatal seizures and brain injury. It has been estimated that approximately 3% of neonatal seizures are related to hypoglycaemia;

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neonatal seizures are seen in 5-13% of VLBW infants and 1-3 per 1000 infants born at term (~30-90 infants annually in England and Wales with hypoglycaemic seizures)

Acute drug withdrawal: Acute drug withdrawal, specifically from opiates, is a rare cause of neonatal seizures and potentially brain injury. Incidence is difficult to estimate.

Appendix 2

Neonatal data

The UK has a long history of using electronic neonatal data for research and now has summary electronic patient data on all admissions to National Health Service (NHS) neonatal units in England, Wales and Scotland. These data are held in a national resource, the National Neonatal Research Database (NNRD). It is important to note that data in the NNRD have undergone detailed cleaning (e.g. to identify duplicates, out of range values, internal inconsistencies, and other potentially erroneous entries), a feedback quality assurance check with clinicians for key items, and merging across often multiple patient episodes to create a single record for each infant. NNRD data are therefore not equivalent to data in the real-time Electronic Patient Records which have undergone no quality assurance procedures and change from second to second.

All neonatal units that contribute data to the NNRD form the UK Neonatal Collaborative, UKNC; currently this comprises 100% of NHS neonatal units in England, Wales and Scotland. NNRD data originate from information entered by clinicians (usually trainees) and nursing staff onto electronic patient record systems, commonly the Bager.net platform at the point of care.

Approximately 400 predefined data items, the Neonatal Data Set²², are extracted quarterly from these electronic patient records to form the NNRD (figure 1).

The Neonatal Data Set is an approved NHS Information Standard hence any neonatal electronic patient record system must be able to capture these items. To date the NNRD holds data on approximately 600 000 patients with 20 000 added quarterly. Data include ICD10 codes and mapping to Systematized Nomenclature of Medicine –Clinical Terms (SNOMED-CT) is underway.

Data items within the Neonatal Data Set can be categorised as:

- Static descriptive variables captured once per baby: such as *birth weight* and *gestational age at birth*
- Episodic variables: such as *episodes of infection* and other clinical outcomes such as *Severe Hypoxic Ischaemic Encephalopathy*
- Daily data variables: treatments such as *anticonvulsant medications*, procedures such as *lumbar puncture*, as well as level of neonatal care

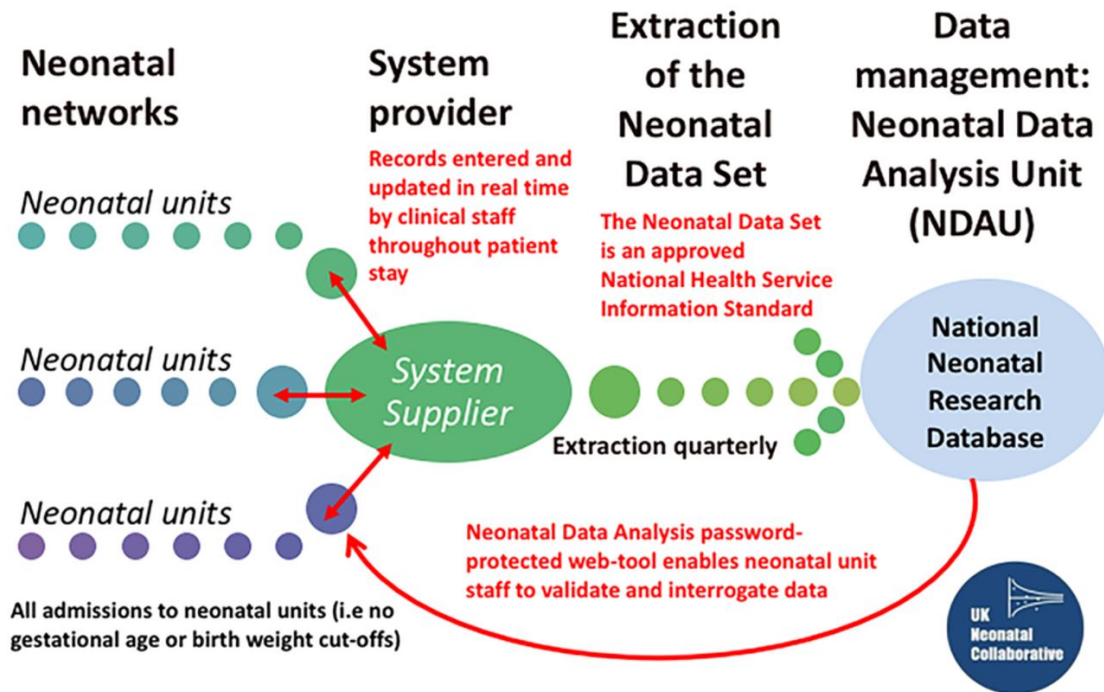
The NNRD holds data from 96% of English NHS neonatal units from 2010 and 100% of English and Welsh NHS neonatal units from 2012. From 2014, 15 of 17 Scottish neonatal units contribute data to the NNRD.

Limited neonatal data are held in other databases including Hospital Episode Statistics (HES) and Office for National Statistics (ONS).

²²http://www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/national_neonatal_data_set/national_neonatal_data_set_-_episodic_and_daily_care_fr.asp?shownav=0

Appendix 2

Figure 1. Data flows to the National Neonatal Research Database



C Gale, and I Morris Arch Dis Child Educ Pract Ed 2016;101:216-218

Appendix 2

Points to consider in relation to using the NNRD

Infants with *brain injury occurring soon after birth* can potentially be identified from the NNRD from multiple different data.

Infants that may have brain injury can be identified through different data item items:

1. Symptoms and signs e.g. *seizures, reduced tone, abnormal reflexes, absent suck*
 - These data fields are commonly incomplete, they tend to only be widely used only in infants with a diagnosis of HIE and this is variable between units
 - Clinical signs (e.g. *reduced tone, abnormal reflexes, absent suck*) are difficult to interpret in preterm infants
2. Treatments e.g. *therapeutic hypothermia (active cooling), exchange transfusion, medications (anti-seizure drugs), neurosurgical procedures (vetriculoperitoneal shunt insertion)*
 - Procedures such as *therapeutic hypothermia* and *exchange transfusion* are carried out with the intention to prevent brain injury
 - Many infants who receive such procedures will not develop detectable brain injury
 - If procedure data items such as *therapeutic hypothermia* and *exchange transfusion* are used to define *brain injury occurring soon after birth* this may discourage the use of such (potentially beneficial) procedures in borderline cases
3. Investigations e.g. *lumbar puncture, cerebral function monitoring, EEG, cranial ultrasound, MRI brain*
 - Investigations such as *lumbar puncture* will be carried out on many babies to 'rule out' central nervous system infection, the majority of whom will have no brain injury
 - Investigations such as *cranial ultrasound* and *MRI brain* are undertaken almost universally in certain groups of infants (e.g. very preterm infants and those receiving therapeutic hypothermia respectively)
4. Diagnosis (diagnosis data are entered at admission, each day and at discharge) e.g. *Hypoxic Ischaemic Encephalopathy grade 3, bacterial meningitis*
 - Many diagnoses which lead to brain injury may not be identified in the neonatal period (i.e. hypoglycaemia which may not become apparent until several year later)
5. Outcome e.g. *abnormal motor outcome at 2 years*
 - These data are only entered for infants <30 weeks gestation at birth
 - There is considerable missing data; 60% of infants <30 weeks gestation at birth had a recorded 2 year follow up consultation in 2015 (54% in 2014)

Definitions of brain injury in current use

Appendix 2

Each Baby Counts is the Royal College of Obstetricians and Gynaecologists' national quality improvement programme to reduce the number of babies who die or are left severely disabled as a result of incidents occurring during term labour.²³

The following neonatal data are being extracted from the NNRD on a quarterly basis:

Gestation age: $\geq 37^{+0}$ weeks^{+days} gestation at birth

Condition	Data items	When recorded in NNRD
<i>Hypoxic Ischaemic Encephalopathy</i>	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Severe Hypoxic Ischaemic Encephalopathy (HIE) 2. Severe Neonatal Encephalopathy 3. Grade 3 Hypoxic Ischaemic Encephalopathy (HIE) <p style="text-align: center;">OR</p> <p>Daily variables: Met one of the following criteria:</p> <ol style="list-style-type: none"> 1. Decreased central tone AND comatose AND seizures 2. Received Therapeutic hypothermia (cooling) 3. Received a diagnosis (daily data variable) of Severe (grade 3) Hypoxic Ischaemic Encephalopathy (HIE) 	<p>Any point</p> <p>Within first 7 days</p>

Comments:

1. Does not include any brain injury in preterm infants
2. Limited to Hypoxic Ischaemic Encephalopathy (HIE) that received therapeutic hypothermia or was severe/grade 3
 - This is a total of ~800 infants annually
3. Defined by treatment (therapeutic hypothermia)
 - Will include infants who do not develop detectable brain injury
 - May discourage use of treatment in borderline cases

²³ <https://www.rcog.org.uk/eachbabycounts>)

Appendix 2

Proposed definitions of *Brain injury occurring at or soon after birth*

We have developed 3 options to illustrate potential approaches to defining *brain injury occurring at or soon after birth*, data items and limitations.

OPTION 1

- Term and near term babies
- *Soon after* defined as injury occurring within 72 hours of birth
- Well defined pathological process
- Conditions detected by discharge

Gestation age: $\geq 35^{+0}$ weeks^{+days} gestation at birth

Condition	Data items	When recorded in NNRD
HIE	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Severe Hypoxic Ischaemic Encephalopathy (HIE) 2. Severe Neonatal Encephalopathy 3. Grade 3 Hypoxic Ischaemic Encephalopathy (HIE) <p style="text-align: center;">OR</p> <p>Daily variables: Met one of the following criteria:</p> <ol style="list-style-type: none"> 1. Decreased central tone AND comatose AND seizures 2. Received Therapeutic hypothermia for 3 consecutive days 3. Received a diagnosis (daily data variable) of Severe (grade 3) Hypoxic Ischaemic Encephalopathy (HIE) 	<p>Any point</p> <p>Within first 72 hours</p>
Perinatal stroke	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Neonatal stroke 2. Infarction: Middle cerebral artery (stroke) 3. Cerebrovascular accident (stroke) 4. Cerebral venous thrombosis 5. Neonatal cerebral ischaemia 	Any point
Intracranial haemorrhage	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Subdural haemorrhage due to birth injury 2. Cerebral haemorrhage due to birth injury 3. Traumatic intraventricular haemorrhage 	Any point

Appendix 2

	<ol style="list-style-type: none"> 4. Subarachnoid haemorrhage due to birth injury 5. Subarachnoid haemorrhage 6. Tentorial tear due to birth injury 7. Intracranial laceration and haemorrhage due to birth injury 8. Small intraventricular haemorrhage (IVH Grade 2) 9. Large intraventricular haemorrhage (IVH Grade 3) 10. Intraventricular haemorrhage/parenchymal haemorrhage (IVH Grade 4) 11. Parenchymal haemorrhage 12. Intracranial Haemorrhage (unknown or unspecified cause) 13. Intracerebral haemorrhage 14. Intracerebral haemorrhage (term infant) 15. Intraventricular haemorrhage (perinatal) 	
Central nervous system infection	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bacterial meningitis 2. Viral meningitis 3. Meningitis – streptococcal 4. Meningitis – bacterial (specific organism) 5. Meningitis – bacterial (unknown or unspecified organism) 6. Meningitis – Candida 7. Candida encephalitis 8. Congenital herpes infection <p>Episodic variables: Any pathogen entered into the <i>suspected infection data</i> field Pathogen in CSF</p>	Any point
Kernicterus	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bilirubin encephalopathy (immune) 2. Kernicterus (unspecified or unknown cause) 3. Kernicterus <p style="text-align: center;">OR</p> <p>Daily variables: Met both of the following criteria:</p> <ol style="list-style-type: none"> 1. Decreased central tone OR comatose OR seizures 2. Received Exchange transfusion 	<72 hours
Hypoglycaemia	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Neonatal hypoglycaemia 2. Iatrogenic neonatal hypoglycaemia <p style="text-align: center;">AND</p>	Any point

Appendix 2

	Daily variables: Decreased central tone OR comatose OR seizures	<72 hours
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Problems:

1. Does not include any brain injury in preterm < 35 weeks infants
2. Defined by treatment (e.g. therapeutic hypothermia)
 - a. Will include infants who do not develop detectable brain injury
 - b. May discourage use of treatment in borderline cases

OPTION 2

- Term and preterm babies
- *Soon after* defined as injury occurring within 72 hours of birth
- Well defined pathological process
- Conditions detected by discharge

Gestation age: No limit

Condition	Data items	When recorded in NNRD
HIE	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Severe Hypoxic Ischaemic Encephalopathy (HIE) 2. Severe Neonatal Encephalopathy 3. Grade 3 Hypoxic Ischaemic Encephalopathy (HIE) <p style="text-align: center;">OR</p> <p>Daily variables: Met one of the following criteria:</p> <ol style="list-style-type: none"> 1. Decreased central tone AND comatose AND seizures 2. Received Therapeutic hypothermia for 3 consecutive days 3. Received a diagnosis (daily data variable) of Severe (grade 3) Hypoxic Ischaemic Encephalopathy (HIE) 	<p>Any point</p> <p>Within first 72 hours</p>
Perinatal stroke	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Neonatal stroke 2. Infarction: Middle cerebral artery (stroke) 3. Cerebrovascular accident (stroke) 4. Cerebral venous thrombosis 5. Neonatal cerebral ischaemia 	Any point

Appendix 2

<p>Intracranial haemorrhage</p>	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Subdural haemorrhage due to birth injury 2. Cerebral haemorrhage due to birth injury 3. Traumatic intraventricular haemorrhage 4. Subarachnoid haemorrhage due to birth injury 5. Subarachnoid haemorrhage 6. Tentorial tear due to birth injury 7. Intracranial laceration and haemorrhage due to birth injury 8. Small intraventricular haemorrhage (IVH Grade 2) 9. Large intraventricular haemorrhage (IVH Grade 3) 10. Intraventricular haemorrhage/parenchymal haemorrhage (IVH Grade 4) 11. Parenchymal haemorrhage 12. Intracranial Haemorrhage (unknown or unspecified cause) 13. Intracerebral haemorrhage 14. Intracerebral haemorrhage (term infant) 15. Intraventricular haemorrhage (perinatal) <p style="text-align: center;">OR</p> <p>Episodic variables: Any of the following codes entered into the <i>cranial ultrasound findings</i> field:</p> <ol style="list-style-type: none"> 1. Small intraventricular haemorrhage (IVH Grade 2) 2. Large intraventricular haemorrhage (IVH Grade 3) 3. Intraventricular haemorrhage/parenchymal haemorrhage (IVH Grade 4) 4. Parenchymal haemorrhage 	<p>Any point</p> <p><72 hours</p>
<p>Central nervous system infection</p>	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bacterial meningitis 2. Viral meningitis 3. Meningitis – streptococcal 4. Meningitis – bacterial (specific organism) 5. Meningitis – bacterial (unknown or unspecified organism) 6. Meningitis – Candida 7. Candida encephalitis 8. Congenital herpes infection <p style="text-align: center;">OR</p> <p>Episodic variables: Any pathogen entered into the <i>suspected infection data</i> field Pathogen in CSF</p>	<p>Any point</p> <p><72 hours when</p>

Appendix 2

		sample collected
Kernicterus	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bilirubin encephalopathy (immune) 2. Kernicterus (unspecified or unknown cause) 3. Kernicterus <p style="text-align: center;">OR</p> <p>Daily variables: Met both of the following criteria:</p> <ol style="list-style-type: none"> 1. Decreased central tone OR comatose OR seizures 2. Received Exchange transfusion 	<p>Any point</p> <p><72 hours</p>
Hypoglycaemia	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Neonatal hypoglycaemia 2. Iatrogenic neonatal hypoglycaemia <p style="text-align: center;">AND</p> <p>Daily variables: Decreased central tone OR comatose OR seizures</p>	<p>Any point</p> <p><72 hours</p>

Problems:

1. Defined by treatment (e.g. therapeutic hypothermia)
 - a. Will include infants who do not develop detectable brain injury
 - b. May discourage use of treatment in borderline cases
2. Will miss many causes of brain injury in preterm infants that occur at or soon after birth but are not easily detected (e.g. conditions which lead to periventricular leucomalacia later)
3. Infants with included diagnoses may not have detectable brain injury (e.g. Small intraventricular haemorrhage (IVH Grade 2))

OPTION 3

- Term and preterm babies
- Considers that very preterm birth (<30 weeks) is a condition with a high risk of brain injury for multiple reasons that are not easily detectable in the neonatal period

Appendix 2

- For very preterm infants *soon after* is defined as occurring during neonatal care
- For infants born >30 weeks gestation *soon after* defined as injury occurring within 72 hours of birth
- Uses 2 year follow up data

Gestation age: The data definitions in *Table 1* apply to all infants born at or above 30 weeks gestation at birth (for infants <30 weeks gestation at birth brain injury will be defined according to *Table 2*, from 2 year follow up data)

Table 1

Condition	Data items	When recorded in NNRD
HIE	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Severe Hypoxic Ischaemic Encephalopathy (HIE) 2. Severe Neonatal Encephalopathy 3. Grade 3 Hypoxic Ischaemic Encephalopathy (HIE) <p style="text-align: center;">OR</p> <p>Daily variables: Met one of the following criteria:</p> <ol style="list-style-type: none"> 1. Decreased central tone AND comatose AND seizures 2. Received Therapeutic hypothermia for 3 consecutive days 3. Received a diagnosis (daily data variable) of Severe (grade 3) Hypoxic Ischaemic Encephalopathy (HIE) 	<p>Any point</p> <p>Within first 72 hours</p>
Perinatal stroke	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Neonatal stroke 2. Infarction: Middle cerebral artery (stroke) 3. Cerebrovascular accident (stroke) 4. Cerebral venous thrombosis 5. Neonatal cerebral ischaemia 	Any point
Intracranial haemorrhage in term infants	<p>Episodic variables: Any of the following diagnosis codes entered into the <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Subdural haemorrhage due to birth injury 2. Cerebral haemorrhage due to birth injury 3. Traumatic intraventricular haemorrhage 4. Subarachnoid haemorrhage due to birth injury 5. Subarachnoid haemorrhage 6. Tentorial tear due to birth injury 7. Intracranial laceration and haemorrhage due to birth injury 	Any point

Appendix 2

	<p>8. Small intraventricular haemorrhage (IVH Grade 2) 9. Large intraventricular haemorrhage (IVH Grade 3) 10. Intraventricular haemorrhage/parenchymal haemorrhage (IVH Grade 4) 11. Parenchymal haemorrhage 12. Intracranial Haemorrhage (unknown or unspecified cause) 13. Intracerebral haemorrhage 14. Intracerebral haemorrhage (term infant) 15. Intraventricular haemorrhage (perinatal)</p>	
Central nervous system infection	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field: 1. Bacterial meningitis 2. Viral meningitis 3. Meningitis – streptococcal 4. Meningitis – bacterial (specific organism) 5. Meningitis – bacterial (unknown or unspecified organism) 6. Meningitis – Candida 7. Candida encephalitis 8. Congenital herpes infection</p> <p style="text-align: center;">OR</p> <p>Episodic variables: Any pathogen entered into the <i>suspected infection data</i> field Pathogen in CSF</p>	<p>Any point</p> <p><72 hours when sample collected</p>
Kernicterus	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field: 1. Bilirubin encephalopathy (immune) 2. Kernicterus (unspecified or unknown cause) 3. Kernicterus</p> <p style="text-align: center;">OR</p> <p>Daily variables: Met both of the following criteria: 1. Decreased central tone OR comatose OR seizures 2. Received Exchange transfusion</p>	<p>Any point</p> <p><72 hours</p>
Hypoglycaemia	<p>Daily variables: Any of the following diagnosis codes entered into the <i>Daily Diagnosis</i> field: 1. Neonatal hypoglycaemia 2. Iatrogenic neonatal hypoglycaemia</p> <p style="text-align: center;">AND</p> <p>Daily variables: Decreased central tone OR comatose OR seizures</p>	<p><72 hours</p> <p><72 hours</p>

Appendix 2

Gestation age: The data definitions in *Table 2* apply to all infants below 30 weeks

Table 2

Condition	Data items	When recorded in NNRD
Preterm brain injury (all causes)	2 year outcome variables: mild/moderate/severe impairment as defined by National Neonatal Audit Programme (NNAP)	2 years

Problems:

1. Defined by treatment (e.g. therapeutic hypothermia)
 - Will include infants who do not develop detectable brain injury
 - May discourage use of treatment in borderline cases
2. Data quality for 2-year outcome data is currently suboptimal (but improving)
3. 2-year outcome data unavailable for 2010

Exclusions

Any definition must clearly explain cases for exclusion (for example congenital abnormalities of brain development that may present in a similar way as *brain injuries occurring at or soon after birth*).

Infants with the following **Episodic variable** diagnosis codes entered into the *Diagnosis at discharge* field will be excluded from the definition

Condition	Data items	When recorded in NNRD
Congenital seizure disorders	TBD	Any point
Congenital infections	TORCH infections	Any point
Congenital brain abnormalities	TBD	Any point

Appendix 3

Brain injury expert group meeting report

Chris Gale, Sabita Uthaya, Eugene Stanikov, Neena Modi, on behalf of the Department of Health expert working group on “*Brain injury occurring during or soon after birth*”

Neonatal Data Analysis Unit, Imperial College London, January 19th 2017

Context

In November 2015, the Secretary of State for Health announced a national ambition to halve the rates of stillbirth, neonatal death, maternal death and brain injuries occurring during or soon after birth, by 2030, with a reduction of 20% by 2020.²⁴ *Brain injuries occurring during or soon after birth* does not have an agreed or standardised definition; in view of this, an expert group was convened by the Department of Health to determine a working definition for the national maternity ambition.

The meeting was convened on 12th January 2017, at Richmond House, London and chaired by Mr Matthew Jolly, National Clinical Director for Maternity Review and Women’s Health. Attendees and their affiliations are provided in Appendix 1.

A briefing paper was circulated in advance of the meeting (Appendix 2). The Department of Health presented the background to the national maternity ambition, and the reasons underpinning the selection of the National Neonatal Research Database (NNRD) as the data source.

A presentation was given by Dr Chris Gale on behalf of the Neonatal Data Analysis Unit (NDAU), Imperial College London, who developed and host the NNRD. This summarised available incidence data on common neonatal conditions that lead to brain injury during or soon after birth, and described the data held in the NNRD.

Aim

To agree a working definition for ‘*brain injuries occurring during or soon after birth*’ for the national maternity ambition, and the following parameters:

1. Gestational age of included infants
2. Time period after birth
3. Conditions /diagnoses
4. The denominator
5. Conditions to be excluded

Initial discussions centred around the overarching aim of the national maternity ambition.

²⁴ <https://www.gov.uk/government/news/new-ambition-to-halve-rate-of-stillbirths-and-infant-deaths>



Discussion

- 1. Gestational age:** Available incidence data indicate that numerically more preterm than term infants are affected by brain injury in the UK each year. There was discussion around whether preterm brain injury was amenable to prevention; data presented by neonatal members of the consensus group indicate that some forms of preterm brain injury, such as intraventricular haemorrhage, are preventable. The consensus decision from the group was to include ***all preterm and term babies admitted to neonatal care (to a neonatal unit)***.
- 2. Time period after birth:** It was noted that the overwhelming majority of neonatal brain injuries occur at birth or within the first three days, in both preterm and term infants. There was discussion about the difficulties inherent in determining the timing of brain injury, which are particularly pronounced in preterm infants (for example preterm white matter injury). For these reasons, the consensus decision of the group was to include ***all brain injuries that are detected during the neonatal unit stay***, and hence recorded in the NNRD.
- 3. Conditions to be included:** There was discussion about neonatal encephalopathy, the clinical manifestation of disordered brain function in the newborn which occurs in many conditions that cause brain injury (such as Hypoxic Ischaemic Encephalopathy (HIE) and neonatal stroke). It was explained by the neonatal clinicians in the group that it can often be difficult to determine the underlying condition in term infants presenting with neonatal encephalopathy. Both the clinical signs observed in neonatal encephalopathy, and specific diagnoses (such as HIE or neonatal stroke) are recorded in the NNRD. A consensus decision was made to include ***term and near term infants with signs consistent with neonatal encephalopathy (altered tone, altered consciousness, seizures), infants with a diagnosis of intracranial haemorrhage, perinatal stroke, HIE, preterm white matter disease, central nervous system infection, and kernicterus (bilirubin encephalopathy)***.
- 4. Denominator:** A consensus decision was made to use ***all live births*** as the denominator for calculating the annual rate of “brain injuries occurring during or soon after birth”.
- 5. Exclusions:** The inclusion of term infants with signs of neonatal encephalopathy has the potential to include a small number of infants with pre-existing conditions (such as congenital neurometabolic disorders) in the definition of *brain injuries occurring during or soon after birth*, unless these are specifically excluded. A consensus decision was made to present data before and after excluding infants diagnosed with the following conditions during their neonatal unit admission: congenital encephalopathies (including inborn errors of metabolism), congenital infections and congenital brain abnormalities.

The final data fields that will be used to extract *brain injuries occurring during or soon after birth* are shown in Appendix 4.



Appendix 4

Brain injury definition: National Neonatal Research Database (NNRD) data fields following consensus meeting

Scope

- All babies admitted to a NHS neonatal unit in England
- Injury detected during neonatal unit stay to discharge
- Annual data, from January 1st 2010 to December 31st 2016

Data source

- Data will be extracted from the National Neonatal Research Database at the Neonatal Data Analysis Unit at Imperial College London.
- The National Neonatal Research Database contains a predefined set of variables (the Neonatal Data Set, an authorised NHS Information Standard) extracted at regular intervals from the Electronic Patient Record of every admission to a NHS neonatal unit in England, Wales, and Scotland, cleaned and merged across multiple patient episodes, to create a single data file for each patient.

Condition	Data items
Term neonatal encephalopathy	Any of the following recorded in any <i>daily care neurology</i> field in babies with a gestational age at birth ≥ 36 weeks: <ol style="list-style-type: none"> 1. Abnormal central tone (increased or decreased) 2. Abnormal consciousness (hyperalert, lethargic, comatose) 3. Seizure occurred
Preterm seizures	Any of the following recorded in any <i>daily care neurology</i> field in any baby with a gestational age at birth < 36 weeks: <ol style="list-style-type: none"> 1. Seizure occurred
HIE	Any of the following recorded in any <i>Diagnosis</i> field: <ol style="list-style-type: none"> 1. Severe Hypoxic Ischaemic Encephalopathy (HIE) 2. Severe Neonatal Encephalopathy 3. Grade 3 Hypoxic Ischaemic Encephalopathy (HIE) 4. Moderate Hypoxic Ischaemic Encephalopathy (HIE) 5. Moderate Neonatal Encephalopathy 6. Grade 2 Hypoxic Ischaemic Encephalopathy (HIE) <p style="text-align: center;">OR</p> The following recorded in <i>daily care neurology</i> field: <ol style="list-style-type: none"> 1. Therapeutic hypothermia induced - for 2 or more consecutive days
Intracranial haemorrhage	Any of the following recorded in any <i>Diagnosis</i> field: <ol style="list-style-type: none"> 1. Subdural haemorrhage due to birth injury 2. Cerebral haemorrhage due to birth injury



	<ol style="list-style-type: none"> 3. Traumatic intraventricular haemorrhage 4. Subarachnoid haemorrhage due to birth injury 5. Subarachnoid haemorrhage 6. Tentorial tear due to birth injury 7. Intracranial laceration and haemorrhage due to birth injury 8. Large intraventricular haemorrhage (IVH Grade 3) 9. Intraventricular haemorrhage/parenchymal 10. Parenchymal haemorrhage 11. haemorrhage (IVH Grade 4) 12. Intracranial Haemorrhage (unknown or unspecified cause) 13. Intracerebral haemorrhage 14. Intracerebral haemorrhage (term infant) 15. Intraventricular haemorrhage (perinatal) 16. Post-haemorrhagic hydrocephalus <p style="text-align: center;">OR</p> <p>Any of the following recorded in any <i>cranial ultrasound findings</i> field:</p> <ol style="list-style-type: none"> 1. Large intraventricular haemorrhage (IVH Grade 3) 2. Intraventricular haemorrhage/parenchymal haemorrhage (IVH Grade 4) 3. Parenchymal haemorrhage <p style="text-align: center;">OR</p> <p>Any of the following recorded in any <i>procedure field</i>:</p> <ol style="list-style-type: none"> 1. Ventriculoperitoneal or other ventricular shunt 2. External ventricular drain 3. Ventricular drain with reservoir 4. Insertion of ventricular peritoneal shunt. 5. Insertion of Rickham reservoir 6. Insertion of ventriculo-atrial CSF shunt 7. Insertion of ventriculo-peritoneal CSF shunt 8. Creation of ventriculoperitoneal shunt
<p>Preterm white matter injury</p>	<p>Any of the following recorded in any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Cystic periventricular leukomalacia <p style="text-align: center;">OR</p> <p>Any of the following recorded in any <i>cranial ultrasound findings</i> field:</p> <ol style="list-style-type: none"> 1. Cystic periventricular leucomalacia
<p>Perinatal stroke</p>	<p>Any of the following recorded in any <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Neonatal stroke 2. Infarction: Middle cerebral artery (stroke) 3. Cerebrovascular accident (stroke) 4. Cerebral venous thrombosis 5. Neonatal cerebral ischaemia



Central nervous system infection	<p>Any of the following diagnosis codes recorded in the <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bacterial meningitis 2. Viral meningitis 3. Meningitis – streptococcal 4. Meningitis – bacterial (specific organism) 5. Meningitis – bacterial (unknown or unspecified organism) 6. Meningitis – Candida 7. Candida encephalitis 8. Congenital herpes infection <p>Any pathogen recorded in the <i>suspected infection data</i> field <i>Pathogen in CSF</i></p>
Kernicterus	<p>Any of the following diagnoses recorded in any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bilirubin encephalopathy (immune) 2. Kernicterus (unspecified or unknown cause) 3. Kernicterus

Exclusions

Data will be presented before and after exclusion of infants with **Term neonatal encephalopathy** (condition defined as above) AND the following diagnosis codes recorded in the *Diagnosis* field during their their neonatal unit admission.

Condition	Data items
Congenital encephalopathies	<p>Episodic variables: Any of the following diagnosis codes entered into any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Congenital neuropathy (unknown or unspecified cause) 2. Congenital myopathy 3. Mitochondrial myopathy 4. Congenital Central Hypoventilation Syndrome (CCHS) 5. Congenital hypertonia 6. Congenital hypotonia - floppy 7. Benign familial neonatal seizures 8. Inborn error of metabolism (description required) 9. Myotonic dystrophy requiring endotracheal intubation and assisted ventilation 10. Disorder of branch chain amino acid metabolism 11. Disorders of fatty acid metabolism 12. Disorders of fatty acid metabolism: carnitine metabolism 13. Disorder of glycine metabolism 14. Disorder of glycine metabolism: Non ketotic hyperglycinaemia 15. Hyperammonaemia of the newborn 16. Disorders of lysine and hydroxylysine metabolism 17. Disorders of ornithine metabolism 18. Disorders of pyruvate metabolism and gluconeogenesis 19. Disorder of carbohydrate metabolism (unknown or



	<p>unspecified cause) 20. Down Syndrome (Trisomy 21) 21. Trisomy 21 22. Edwards Syndrome (Trisomy 18) 23. Trisomy 18 24. Patau Syndrome (Trisomy 13) 25. Trisomy 13</p>
Congenital infections	<p>Episodic variables: Any of the following diagnosis codes entered into any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Congenital viral disease (specify) 2. Syphilis - latent congenital 3. Congenital rubella syndrome 4. Congenital cytomegalovirus infection 5. Congenital herpes [herpes simplex] infection 6. Other congenital viral diseases 7. Congenital viral disease (unknown or unspecified cause) 8. Congenital toxoplasmosis
Congenital brain abnormalities	<p>Episodic variables: Any of the following diagnosis codes entered into any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Malformations of aqueduct of Sylvius 2. Atresia of foramina of Magendie and Luschka 3. Atresia of foramina of Magendie and Luschka 4. Other congenital hydrocephalus 5. X linked congenital hydrocephalus 6. Congenital hydrocephalus (unknown or unspecified cause) 7. Congenital hydrocephalus 8. Lissencephaly 9. Vermal agenesis 10. Septum pelucidum absence – congenital 11. Congenital malformations of corpus callosum 12. Arhinencephaly 13. Holoprosencephaly 14. Other reduction deformities of brain 15. Septo-optic dysplasia 16. Other specified congenital malformations of brain 17. Congenital malformation of brain (unknown or unspecified cause) 18. Other congenital malformations of brain 19. Cervical spina bifida with hydrocephalus 20. Thoracic spina bifida with hydrocephalus 21. Spina bifida (unknown or unspecified cause) 22. Spina bifida 23. Amyelia 24. Hypoplasia and dysplasia of spinal cord 25. Other specified congenital malformations of spinal cord 26. Congenital malformation of spinal cord (unknown or unspecified cause) 27. Nerve palsies – congenital



	<ul style="list-style-type: none">28. Arnold-Chiari syndrome29. Other specified congenital malformations of nervous system30. Congenital malformation of nervous system (unknown or unspecified cause)31. Other congenital malformations of nervous system32. Congenital Hydrocephalus
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Authors: Chris Gale, Sabita Uthaya, Eugene Stanikov, Neena Modi, on behalf of the DH expert working group on “*Brain injury occurring during or soon after birth*”, Neonatal Data Analysis Unit

Date of production: January 19th 2017





Department
of Health

Maternity Safety Programme Team
Richmond House
79 Whitehall
London
SW1A 2NS

9 January 2017

Dear United Kingdom Neonatal Collaborative lead,

Department of Health National Maternity Ambition

Last year, the Secretary of State for Health announced a **National Maternity Ambition** to reduce the rate of stillbirths, neonatal deaths and brain injuries occurring during or soon after birth. There are some data describing stillbirths and neonatal deaths, but it is not clear how 'brain injury occurring during or soon after birth' should be defined or how data defining it should be recorded.

In response to this, the Department of Health is convening an expert group comprising the Neonatal Data Analysis Unit and other stakeholders to agree consensus on how to define 'brain injury occurring during or soon after birth'. To inform this process, the Department of Health will be using de-identified data held in the Neonatal Research Database (NNRD).

The intention of this work is to allow ongoing assessment of progress towards the ambition set out by the Secretary of State for Health.

This letter is for information only and requires no action. If you have any questions about this work please contact:

Nilum Patel

Nilum.patel@dh.gsi.gov.uk

02072103870

Yours faithfully,

Matthew Jolly
National Clinical Director for The Maternity Review and Women's Health Acute Medical Directorate
NHS England



Appendix 6

English neonatal units that contributed data to the National Neonatal Research Database (NNRD), by month, in 2010 and 2011

X = contributed data to the NNRD in that calendar month

Please note that there were neonatal unit closures and new neonatal units that opened during 2010 and 2011.

	2010											
Hospital	JAN	FEB	MAR	APRIL	MAY	JUN	JULY	AUG	SEPT	OCT	NOV	DEC
AIREDALE GENERAL HOSPITAL									X	X	X	X
ALEXANDRA HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ARROWE PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BARNET HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BARNSELY DISTRICT GENERAL HOSPITAL				X	X	X	X	X	X	X	X	X
BASILDON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BASINGSTOKE & NORTH HAMPSHIRE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BASSETLAW DISTRICT GENERAL HOSPITAL				X	X	X	X	X	X	X	X	X
BEDFORD HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BIRMINGHAM HEARTLANDS HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BIRMINGHAM WOMEN'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BRADFORD ROYAL INFIRMARY			X	X	X	X	X	X	X	X	X	X
BROOMFIELD HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CALDERDALE ROYAL HOSPITAL								X	X	X	X	X
CHASE FARM HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CHELSEA & WESTMINSTER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CHELTENHAM GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



CHESTERFIELD & NORTH DERBYSHIRE ROYAL HOSPITAL				X	X	X	X	X	X	X	X	X
CITY HOSPITAL, BIRMINGHAM	X	X	X	X	X	X	X	X	X	X	X	X
COLCHESTER GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CONQUEST HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
COUNTESS OF CHESTER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
COUNTY HOSPITAL, STAFFORDSHIRE			X	X	X	X	X	X	X	X	X	X
CROYDON UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CUMBERLAND INFIRMARY												
DARENT VALLEY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DARLINGTON MEMORIAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DERRIFORD HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DEWSBURY & DISTRICT HOSPITAL					X	X	X	X	X	X	X	X
DIANA PRINCESS OF WALES HOSPITAL				X	X	X	X	X	X	X	X	X
DONCASTER ROYAL INFIRMARY				X	X	X	X	X	X	X	X	X
DORSET COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EALING HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EAST SURREY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EASTBOURNE DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EPSOM GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
FAIRFIELD GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
FRIMLEY PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
FURNESS GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GEORGE ELIOT HOSPITAL										X	X	X
GLOUCESTERSHIRE ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GOOD HOPE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GREAT WESTERN HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GUY'S & ST THOMAS' HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



HARROGATE DISTRICT HOSPITAL			X	X	X	X	X	X	X	X	X	X
HEREFORD COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HILLINGDON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HINCHINGBROOKE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HOMERTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HULL ROYAL INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
IPSWICH HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
JAMES COOK UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
JAMES PAGET HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KETTERING GENERAL HOSPITAL		X	X	X	X	X	X	X	X	X	X	X
KING GEORGE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KING'S COLLEGE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KING'S MILL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KINGSTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LANCASHIRE WOMEN & NEWBORN CENTRE	X	X	X	X	X	X	X	X	X	X	X	X
LEEDS NEONATAL SERVICE				X	X	X	X	X	X	X	X	X
LEICESTER NEONATAL SERVICE	X	X	X	X	X	X	X	X	X	X	X	X
LEIGHTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LINCOLN COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LISTER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LIVERPOOL WOMEN'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LUTON & DUNSTABLE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MACCLESFIELD DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MAIDSTONE GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MANOR HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MEDWAY MARITIME HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MILTON KEYNES FOUNDATION TRUST HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



NEW CROSS HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NEWHAM GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORFOLK & NORWICH UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORTH BRISTOL NHS TRUST (SOUTHMEAD)	X	X	X	X	X	X	X	X	X	X	X	X
NORTH DEVON DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORTH MANCHESTER GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORTH MIDDLESEX UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORTHAMPTON GENERAL HOSPITAL												
NORTHWICK PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NOTTINGHAM CITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NOTTINGHAM UNIVERSITY HOSPITAL (QMC)	X	X	X	X	X	X	X	X	X	X	X	X
ORMSKIRK DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
OXFORD UNIVERSITY HOSPITALS, HORTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
OXFORD UNIVERSITY HOSPITALS, JOHN RADCLIFFE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PETERBOROUGH CITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PILGRIM HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PINDERFIELDS GENERAL HOSPITAL				X	X	X	X	X	X	X	X	X
POOLE HOSPITAL NHS FOUNDATION TRUST	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ALEXANDRA HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ANNE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ROYAL UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ALEXANDRA HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN CHARLOTTE'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH HOSPITAL, GATESHEAD	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH HOSPITAL, KING'S LYNN	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH HOSPITAL, WOOLWICH	X	X	X	X	X	X	X	X	X	X	X	X



QUEEN ELIZABETH II HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH THE QUEEN MOTHER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN MARY'S SIDCUP	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN'S HOSPITAL, BURTON ON TRENT												X
QUEEN'S HOSPITAL, ROMFORD	X	X	X	X	X	X	X	X	X	X	X	X
ROCHDALE INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
ROSIE MATERNITY HOSPITAL, ADDENBROOKES	X	X	X	X	X	X	X	X	X	X	X	X
ROTHERHAM DISTRICT GENERAL HOSPITAL				X	X	X	X	X	X	X	X	X
ROYAL ALBERT EDWARD INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL BERKSHIRE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL BOLTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL CORNWALL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL DERBY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL DEVON & EXETER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL HAMPSHIRE COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL LANCASTER INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL OLDHAM HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL PRESTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL SHREWSBURY HOSPITAL			X	X	X	X	X	X	X	X	X	X
ROYAL STOKE UNIVERSITY HOSPITAL												
ROYAL SURREY COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL SUSSEX COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL UNITED HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL VICTORIA INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
RUSSELLS HALL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SALFORD ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SALISBURY DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



SANDWELL GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SCARBOROUGH GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SCUNTHORPE GENERAL HOSPITAL			X	X	X	X	X	X	X	X	X	X
SHEFFIELD CHILDREN'S HOSPITAL				X	X	X	X	X	X	X	X	X
SOUTH TYNESIDE DISTRICT HOSPITAL						X	X	X	X	X	X	X
SOUTHEND HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST GEORGE'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST HELIER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST MARY'S HOSPITAL, IOW	X	X	X	X	X	X	X	X	X	X	X	X
ST MARY'S HOSPITAL, LONDON	X	X	X	X	X	X	X	X	X	X	X	X
ST MARY'S HOSPITAL, MANCHESTER	X	X	X	X	X	X	X	X	X	X	X	X
ST MICHAEL'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST PETER'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST RICHARD'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
STEPPING HILL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
STOKE MANDEVILLE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SUNDERLAND ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
TAMESIDE GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
TAUNTON & SOMERSET HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
THE JESSOP WING, SHEFFIELD			X	X	X	X	X	X	X	X	X	X
THE ROYAL FREE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
THE ROYAL LONDON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
THE ROYAL LONDON HOSPITAL - CONSTANCE GREEN	X	X	X	X	X	X	X	X	X	X	X	X
TORBAY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
TUNBRIDGE WELLS HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY COLLEGE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL COVENTRY								X	X	X	X	X



UNIVERSITY HOSPITAL LEWISHAM	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF NORTH DURHAM	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF NORTH TEES	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF SOUTH MANCHESTER	X	X	X	X	X	X	X	X	X	X	X	X
VICTORIA HOSPITAL, BLACKPOOL	X	X	X	X	X	X	X	X	X	X	X	X
WANSBECK GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WARRINGTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WARWICK HOSPITAL												X
WATFORD GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WEST CUMBERLAND HOSPITAL												
WEST MIDDLESEX UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WEST SUFFOLK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WEXHAM PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WHIPPS CROSS UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WHISTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WHITTINGTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WILLIAM HARVEY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WORCESTERSHIRE ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WORTHING HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
YEOVIL DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
YORK DISTRICT HOSPITAL												



	2011											
Hospital	JAN	FEB	MAR	APRIL	MAY	JUN	JULY	AUG	SEPT	OCT	NOV	DEC
AIREDALE GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ALEXANDRA HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ARROWE PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BARNET HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BARNSELY DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BASILDON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BASINGSTOKE & NORTH HAMPSHIRE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BASSETLAW DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BEDFORD HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BIRMINGHAM HEARTLANDS HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BIRMINGHAM WOMEN'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
BRADFORD ROYAL INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
BROOMFIELD HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CALDERDALE ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CHASE FARM HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CHELSEA & WESTMINSTER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CHELTENHAM GENERAL HOSPITAL	X											
CHESTERFIELD & NORTH DERBYSHIRE ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CITY HOSPITAL, BIRMINGHAM	X	X	X	X	X	X	X	X	X	X	X	X
COLCHESTER GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
CONQUEST HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
COUNTESS OF CHESTER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
COUNTY HOSPITAL, STAFFORDSHIRE	X	X	X	X	X	X	X	X	X	X	X	X
CROYDON UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



CUMBERLAND INFIRMARY				X	X	X	X	X	X	X	X	X
DARENT VALLEY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DARLINGTON MEMORIAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DERRIFORD HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DEWSBURY & DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DIANA PRINCESS OF WALES HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
DONCASTER ROYAL INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
DORSET COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EALING HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EAST SURREY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EASTBOURNE DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
EPSOM GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
FAIRFIELD GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
FRIMLEY PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
FURNESS GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GEORGE ELIOT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GLOUCESTERSHIRE ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GOOD HOPE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GREAT WESTERN HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
GUY'S & ST THOMAS' HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HARROGATE DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HEREFORD COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HILLINGDON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HINCHINGBROOKE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HOMERTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
HULL ROYAL INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
IPSWICH HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



JAMES COOK UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
JAMES PAGET HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KETTERING GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KING GEORGE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KING'S COLLEGE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KING'S MILL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
KINGSTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LANCASHIRE WOMEN & NEWBORN CENTRE	X	X	X	X	X	X	X	X	X	X	X	X
LEEDS NEONATAL SERVICE	X	X	X	X	X	X	X	X	X	X	X	X
LEICESTER NEONATAL SERVICE	X	X	X	X	X	X	X	X	X	X	X	X
LEIGHTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LINCOLN COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LISTER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LIVERPOOL WOMEN'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
LUTON & DUNSTABLE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MACCLESFIELD DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MAIDSTONE GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X		
MANOR HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MEDWAY MARITIME HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
MILTON KEYNES FOUNDATION TRUST HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NEW CROSS HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NEWHAM GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORFOLK & NORWICH UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORTH BRISTOL NHS TRUST (SOUTHMEAD)	X	X	X	X	X	X	X	X	X	X	X	X
NORTH DEVON DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORTH MANCHESTER GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NORTH MIDDLESEX UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



NORTHAMPTON GENERAL HOSPITAL												
NORTHWICK PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NOTTINGHAM CITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
NOTTINGHAM UNIVERSITY HOSPITAL (QMC)	X	X	X	X	X	X	X	X	X	X	X	X
ORMSKIRK DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
OXFORD UNIVERSITY HOSPITALS, HORTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
OXFORD UNIVERSITY HOSPITALS, JOHN RADCLIFFE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PETERBOROUGH CITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PILGRIM HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PINDERFIELDS GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
POOLE HOSPITAL NHS FOUNDATION TRUST	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ALEXANDRA HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ANNE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
PRINCESS ROYAL UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ALEXANDRA HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN CHARLOTTE'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH HOSPITAL, GATESHEAD	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH HOSPITAL, KING'S LYNN	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH HOSPITAL, WOOLWICH	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN ELIZABETH II HOSPITAL	X	X	X	X	X	X	X	X	X	X		
QUEEN ELIZABETH THE QUEEN MOTHER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN MARY'S SIDCUP	X											
QUEEN'S HOSPITAL, BURTON ON TRENT	X	X	X	X	X	X	X	X	X	X	X	X
QUEEN'S HOSPITAL, ROMFORD	X	X	X	X	X	X	X	X	X	X	X	X
ROCHDALE INFIRMARY	X	X	X	X	X	X						
ROSIE MATERNITY HOSPITAL, ADDENBROOKES	X	X	X	X	X	X	X	X	X	X	X	X



ROTHERHAM DISTRICT GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL ALBERT EDWARD INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL BERKSHIRE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL BOLTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL CORNWALL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL DERBY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL DEVON & EXETER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL HAMPSHIRE COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL LANCASTER INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL OLDHAM HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL PRESTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL SHREWSBURY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL STOKE UNIVERSITY HOSPITAL												
ROYAL SURREY COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL SUSSEX COUNTY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL UNITED HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ROYAL VICTORIA INFIRMARY	X	X	X	X	X	X	X	X	X	X	X	X
RUSSELLS HALL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SALFORD ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	
SALISBURY DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SANDWELL GENERAL HOSPITAL	X											
SCARBOROUGH GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SCUNTHORPE GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SHEFFIELD CHILDREN'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	
SOUTH TYNESIDE DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SOUTHEND HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST GEORGE'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



ST HELIER HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST MARY'S HOSPITAL, IOW	X	X	X	X	X	X	X	X	X	X	X	X
ST MARY'S HOSPITAL, LONDON	X	X	X	X	X	X	X	X	X	X	X	X
ST MARY'S HOSPITAL, MANCHESTER	X	X	X	X	X	X	X	X	X	X	X	X
ST MICHAEL'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST PETER'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
ST RICHARD'S HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
STEPPING HILL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
STOKE MANDEVILLE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
SUNDERLAND ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
TAMESIDE GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
TAUNTON & SOMERSET HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
THE JESSOP WING, SHEFFIELD	X	X	X	X	X	X	X	X	X	X	X	X
THE ROYAL FREE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
THE ROYAL LONDON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
THE ROYAL LONDON HOSPITAL - CONSTANCE GREEN	X	X	X	X	X	X	X	X	X	X	X	X
TORBAY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
TUNBRIDGE WELLS HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY COLLEGE HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL COVENTRY	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL LEWISHAM	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF NORTH DURHAM	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF NORTH TEES	X	X	X	X	X	X	X	X	X	X	X	X
UNIVERSITY HOSPITAL OF SOUTH MANCHESTER	X	X	X	X	X	X	X	X	X	X	X	X
VICTORIA HOSPITAL, BLACKPOOL	X	X	X	X	X	X	X	X	X	X	X	X
WANSBECK GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X



WARRINGTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WARWICK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WATFORD GENERAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WEST CUMBERLAND HOSPITAL				X	X	X	X	X	X	X	X	X
WEST MIDDLESEX UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WEST SUFFOLK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WEXHAM PARK HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WHIPPS CROSS UNIVERSITY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WHISTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WHITTINGTON HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WILLIAM HARVEY HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WORCESTERSHIRE ROYAL HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
WORTHING HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
YEOVIL DISTRICT HOSPITAL	X	X	X	X	X	X	X	X	X	X	X	X
YORK DISTRICT HOSPITAL												



Appendix 7

Final brain injury definition: National Neonatal Research Database (NNRD) data fields

Scope

- All babies admitted to a NHS neonatal unit in England
- Injury detected during neonatal unit stay to discharge
- Annual data, from January 1st 2010 to December 31st 2015

Data source

- Data will be extracted from the National Neonatal Research Database (NNRD) at the Neonatal Data Analysis Unit at Imperial College London.
- The NNRD contains a predefined set of variables (the Neonatal Data Set, an authorised NHS Information Standard) extracted at regular intervals from the Electronic Patient Record of every admission to a NHS neonatal unit in England, Wales, and Scotland, cleaned and merged across multiple patient episodes, to create a single data file for each patient.

Condition	Data items
HIE	<p>Any of the following recorded in any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Severe Hypoxic Ischaemic Encephalopathy (HIE) 2. Severe Neonatal Encephalopathy 3. Grade 3 Hypoxic Ischaemic Encephalopathy (HIE) 4. Moderate Hypoxic Ischaemic Encephalopathy (HIE) 5. Moderate Neonatal Encephalopathy 6. Grade 2 Hypoxic Ischaemic Encephalopathy (HIE) <p style="text-align: center;">OR</p> <p>The following recorded in <i>daily care neurology</i> field:</p> <ol style="list-style-type: none"> 1. Therapeutic hypothermia induced - for 2 or more consecutive days
Intracranial haemorrhage	<p>Any of the following recorded in any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Subdural haemorrhage due to birth injury 2. Cerebral haemorrhage due to birth injury 3. Traumatic intraventricular haemorrhage 4. Subarachnoid haemorrhage due to birth injury 5. Subarachnoid haemorrhage 6. Tentorial tear due to birth injury 7. Intracranial laceration and haemorrhage due to birth injury 8. Large intraventricular haemorrhage (IVH Grade 3) 9. Intraventricular haemorrhage/parenchymal 10. Parenchymal haemorrhage 11. haemorrhage (IVH Grade 4) 12. Intracranial Haemorrhage (unknown or unspecified cause)



	<p>13. Intracerebral haemorrhage 14. Intracerebral haemorrhage (term infant) 15. Intraventricular haemorrhage (perinatal) 16. Post-haemorrhagic hydrocephalus</p> <p style="text-align: center;">OR</p> <p>Any of the following recorded in any <i>cranial ultrasound findings</i> field:</p> <ol style="list-style-type: none"> 1. Large intraventricular haemorrhage (IVH Grade 3) 2. Intraventricular haemorrhage/parenchymal haemorrhage (IVH Grade 4) 3. Parenchymal haemorrhage <p style="text-align: center;">OR</p> <p>Any of the following recorded in any <i>procedure</i> field:</p> <ol style="list-style-type: none"> 1. Ventriculoperitoneal or other ventricular shunt 2. External ventricular drain 3. Ventricular drain with reservoir 4. Insertion of ventricular peritoneal shunt. 5. Insertion of Rickham reservoir 6. Insertion of ventriculo-atrial CSF shunt 7. Insertion of ventriculo-peritoneal CSF shunt 8. Creation of ventriculoperitoneal shunt
Preterm white matter injury	<p>Any of the following recorded in any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Cystic periventricular leukomalacia <p style="text-align: center;">OR</p> <p>Any of the following recorded in any <i>cranial ultrasound findings</i> field:</p> <ol style="list-style-type: none"> 1. Cystic periventricular leucomalacia
Perinatal stroke	<p>Any of the following recorded in any <i>Diagnosis at discharge</i> field:</p> <ol style="list-style-type: none"> 1. Neonatal stroke 2. Infarction: Middle cerebral artery (stroke) 3. Cerebrovascular accident (stroke) 4. Cerebral venous thrombosis 5. Neonatal cerebral ischaemia
Central nervous system infection	<p>Any of the following diagnosis codes recorded in the <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bacterial meningitis 2. Viral meningitis 3. Meningitis – streptococcal 4. Meningitis – bacterial (specific organism) 5. Meningitis – bacterial (unknown or unspecified organism) 6. Meningitis – Candida 7. Candida encephalitis 8. Congenital herpes infection <p>Any pathogen recorded in the <i>suspected infection data</i> field <i>Pathogen in CSF</i></p>
Kernicterus	<p>Any of the following diagnoses recorded in any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Bilirubin encephalopathy (immune)



	<ol style="list-style-type: none"> 2. Kernicterus (unspecified or unknown cause) 3. Kernicterus
Seizures	<p>Any of the following recorded in any <i>daily care neurology</i> field:</p> <ol style="list-style-type: none"> 1. Seizure occurred

Exclusions

Data will be presented before and after exclusion of infants with **seizures** (condition defined as above) AND the following diagnosis codes recorded in the *Diagnosis* field during their their neonatal unit admission.

Condition	Data items
Congenital encephalopathies	<p>Episodic variables: Any of the following diagnosis codes entered into any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Congenital neuropathy (unknown or unspecified cause) 2. Congenital myopathy 3. Mitochondrial myopathy 4. Congenital Central Hypoventilation Syndrome (CCHS) 5. Congenital hypertonia 6. Congenital hypotonia - floppy 7. Benign familial neonatal seizures 8. Inborn error of metabolism (description required) 9. Myotonic dystrophy requiring endotracheal intubation and assisted ventilation 10. Disorder of branch chain amino acid metabolism 11. Disorders of fatty acid metabolism 12. Disorders of fatty acid metabolism: carnitine metabolism 13. Disorder of glycine metabolism 14. Disorder of glycine metabolism: Non ketotic hyperglycinaemia 15. Hyperammonaemia of the newborn 16. Disorders of lysine and hydroxylysine metabolism 17. Disorders of ornithine metabolism 18. Disorders of pyruvate metabolism and gluconeogenesis 19. Disorder of carbohydrate metabolism (unknown or unspecified cause) 20. Down Syndrome (Trisomy 21) 21. Trisomy 21 22. Edwards Syndrome (Trisomy 18) 23. Trisomy 18 24. Patau Syndrome (Trisomy 13) 25. Trisomy 13
Congenital infections	<p>Episodic variables: Any of the following diagnosis codes entered into any <i>Diagnosis</i> field:</p> <ol style="list-style-type: none"> 1. Congenital viral disease (specify) 2. Syphilis - latent congenital 3. Congenital rubella syndrome 4. Congenital cytomegalovirus infection 5. Congenital herpes [herpes simplex] infection



	<ul style="list-style-type: none"> 6. Other congenital viral diseases 7. Congenital viral disease (unknown or unspecified cause) 8. Congenital toxoplasmosis
Congenital brain abnormalities	<p>Episodic variables: Any of the following diagnosis codes entered into any <i>Diagnosis</i> field:</p> <ul style="list-style-type: none"> 1. Malformations of aqueduct of Sylvius 2. Atresia of foramina of Magendie and Luschka 3. Atresia of foramina of Magendie and Luschka 4. Other congenital hydrocephalus 5. X linked congenital hydrocephalus 6. Congenital hydrocephalus (unknown or unspecified cause) 7. Congenital hydrocephalus 8. Lissencephaly 9. Vermal agenesis 10. Septum pelucidum absence – congenital 11. Congenital malformations of corpus callosum 12. Arhinencephaly 13. Holoprosencephaly 14. Other reduction deformities of brain 15. Septo-optic dysplasia 16. Other specified congenital malformations of brain 17. Congenital malformation of brain (unknown or unspecified cause) 18. Other congenital malformations of brain 19. Cervical spina bifida with hydrocephalus 20. Thoracic spina bifida with hydrocephalus 21. Spina bifida (unknown or unspecified cause) 22. Spina bifida 23. Amyelia 24. Hypoplasia and dysplasia of spinal cord 25. Other specified congenital malformations of spinal cord 26. Congenital malformation of spinal cord (unknown or unspecified cause) 27. Nerve palsies – congenital 28. Arnold-Chiari syndrome 29. Other specified congenital malformations of nervous system 30. Congenital malformation of nervous system (unknown or unspecified cause) 31. Other congenital malformations of nervous system 32. Congenital Hydrocephalus

Authors: Chris Gale, Sabita Uthaya, Eugene Stanikov, Neena Modi, on behalf of the DH expert working group on “*Brain injury occurring during or soon after birth*”, Neonatal Data Analysis Unit

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