UK National Neonatal Research Database

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Data source Human Other

Administrative details

Administrative details

Data source ID

45867

Data source acronym

NNRD

Data holder

Imperial College London

Data source type

Other

Data source type, other

Electronic health records, Admissions to National Health Service Neonatal Units

Main financial support

Other

Care setting

Hospital inpatient care

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

Yes

Description of the qualification

ISO

Data source website

Neonatal Data Analysis Unit website

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Data source regions and languages

Data source countries

Isle of Man

United Kingdom

Data source languages

English

Data source regions

England

Scotland

Wales [Cymru GB-CYM]

Data source establishment

Data source established

15/06/2007

Data source time span

First collection: 15/06/2007

The date when data started to be collected or extracted.

Publications

Data source publications

Impact of postnatal dexamethasone timing on preterm mortality and bronchopulmonary dysplasia: a propensity score analysis.

Two-year neurodevelopmental data for preterm infants born over an 11-year period in England and Wales, 2008-2018: a retrospective study using the National Neonatal Research Database

Characteristics and outcomes of neonates hospitalised with SARS-CoV-2 infection in the UK by variant: a prospective national cohort study

Paediatric intensive care admissions of preterm children born <32 weeks gestation: a national retrospective cohort study using data linkage

Effect of national guidance on survival for babies born at 22 weeks’ gestation in England and Wales: population based cohort study

Outcomes in very preterm infants receiving an exclusive human milk diet, or their own mother's milk supplemented with preterm formula

Observational cohort study of use of caffeine in preterm infants and association between early caffeine use and neonatal outcomes

Association between Early Feeding Patterns and Neonatal Outcomes in Very Preterm Infants: A Retrospective Cohort Study

Neonatal outcomes of maternal SARS-CoV-2 infection in the UK: a prospective cohort study using active surveillance.

The contribution of hypertensive disorders of pregnancy to late preterm and term admissions to neonatal units in the UK 2012-2020 and opportunities to avoid admission: A population-based study using the National Neonatal Research Database

Early antibiotic use and incidence of necrotising enterocolitis in very preterm infants: a protocol for a UK based observational study using routinely recorded data.

Preterm Brain Injury and Neurodevelopmental Outcomes: A Meta-analysis.

Pilot feasibility study of a digital technology approach to the systematic electronic capture of parent-reported data on cognitive and language development in children aged 2 years.

Involving multiple stakeholders in assessing and reviewing a novel data visualisation tool for a national neonatal data asset

Data-driven approach to understanding neonatal palliative care needs in England and Wales: a population-based study 2015-2020

Neonatal health care costs of very preterm babies in England: a retrospective analysis of a national birth cohort.

Postnatal corticosteroid use for prevention or treatment of bronchopulmonary dysplasia in England and Wales 2012-2019: a retrospective population cohort study.

Views of parents, adults born preterm and professionals on linkage of real-world data of preterm babies

Effect of an Exclusive Human Milk Diet on the Gut Microbiome in Preterm Infants: A Randomized Clinical Trial

Changes in neonatal admissions, care processes and outcomes in England and Wales during the COVID-19 pandemic: a whole population cohort study

Follow-up study of infants recruited to the randomised, placebo-controlled trial of azithromycin for the prevention of chronic lung disease of prematurity in preterm infants-study protocol for the AZTEC-FU study.

Birthweight and patterns of postnatal weight gain in very and extremely preterm babies in England and Wales from 2008-2019

Identification of variation in nutritional practice in neonatal units in England and association with clinical outcomes using agnostic machine learning

Association of Maternal Diabetes With Neonatal Outcomes of Very Preterm and Very Low-Birth-Weight Infants: An International Cohort Study

Scoping review shows wide variation in the definitions of bronchopulmonary dysplasia in preterm infants and calls for a consensus

Respiratory Management of Extremely Preterm Infants: An International Survey

Validity of neurodevelopmental outcomes of children born very preterm assessed during routine clinical follow-up in England

Pilot study to establish a prospective neonatal cohort: Study of Preterm Infants and Neurodevelopmental Genes (SPRING)

Outcomes following early parenteral nutrition use in preterm neonates: Protocol for an observational study

A framework to address key issues of neonatal service configuration in England: the NeoNet multimethods study

Routine gastric residual volume measurement to guide enteral feeding in mechanically ventilated infants and children: the GASTRIC feasibility study

Neonatal outcomes of very preterm or very low birth weight triplets

Recent advances in the genetics of preterm birth

A systematic review of administrative and clinical databases of infants admitted to neonatal units

Feeding during neonatal therapeutic hypothermia, assessed using routinely collected National Neonatal Research Database data: a retrospective, UK population-based cohort study

Neonatal encephalopathy with Group B streptococcal disease worldwide: systematic review, investigator group datasets, and meta-analysis

Core outcomes in neonatology: Development of a core outcome set for neonatal research

Unit-level variations in healthcare professionals' availability for preterm neonates <29 weeks' gestation: an international survey.

Information technology infrastructure, quality improvement and re-search: the UK National Neonatal Research Database

Developing routinely recorded clinical data from electronic patient records as a national resource to improve neonatal health care: the Medicines for Neonates research programme

Development and validation of a simplified score to predict neonatal mortality risk among neonates weighing 2000 g or less (NMR-2000): an analysis using data from the UK and The Gambia

Protocol for a scoping review to support development of a CONSORT extension for randomised controlled trials using cohorts and routinely collected health data

Optimising nutrition during therapeutic hypothermia

Improving the efficiency and impact of clinical research: a game changer for 21st century neonatology

Inter-center variability in neonatal outcomes of preterm infants: A longitudinal evaluation of 298 neonatal units in 11 countries

A systematic review identifying common data items in neonatal trials and assessing their completeness in routinely recorded United Kingdom national neonatal data.

Survival in Very Preterm Infants: An International Comparison of 10 National Neonatal Networks

Association of early postnatal transfer and birth outside a tertiary hospital with mortality and severe brain injury in extremely preterm infants: observational cohort study with propensity score matching eNewborn: The information technology revolution and challenges for neonatal networks

Evaluating preterm care across Europe using the eNewborn European Network database

The effect of surfactant dose on outcomes in preterm infants with Respiratory Distress Syndrome: the OPTI-SURF study protocol

The WHEAT pilot trial-WithHolding Enteral feeds Around packed red cell Transfusion to prevent necrotising enterocolitis in preterm neonates: a multicentre, electronic patient record randomised controlled point-of-care pilot trial

Neonatal outcomes of extremely preterm twins by sex pairing: an international cohort study

Can we reduce the burden of the current UK guidelines for Retinopathy of Prematurity (ROP) screening?

Sharing data to accelerate medicines development and improve neonatal care: data standards and harmonized definitions

Incidence of neonatal necrotising enterocolitis in high income countries: a systematic review

Study protocol: optimising newborn nutrition during and after neonatal therapeutic hypothermia in the United Kingdom: observational study of routinely collected data using propensity matching

Incidence and enteral feed antecedents of severe neonatal necrotising enterocolitis across neonatal networks in England, 2012-13: a whole-population surveillance study.

Development of a gestational age-specific case definition for neonatal necrotizing enterocolitis

Use of pasteurised human donor milk across neonatal networks

Trends in the Incidence and Management of Hypoxic-Ischaemic Encephalopathy in the Therapeutic Hypothermia Era: A National Population Study.

Better use of data to improve parent satisfaction (BUDS): protocol for a prospective before-and-after pilot study employing mixed methods to improve parent experience of neonatal care

Survival of very preterm infants admitted to neonatal care in England 2008–2014: time trends and regional variation

Perinatal health services organization for preterm births: a multinational comparison

A methodological framework for assessing agreement between cost-effectiveness outcomes estimated using alternative sources of data on treatment costs and effects for trial-based economic evaluations

Optimising neonatal service provision for preterm babies born between 27 and 31 weeks gestation in England (OPTI-PREM), using national data, qualitative research and economic analysis: a study protocol

The United Kingdom National Neonatal Research Database: a validation study.

Administration of parenteral nutrition during therapeutic hypothermia: a population level observational study using routinely collected data held in the National Neonatal Research Database

Can we estimate the length of stay of very preterm multiples?

Brain Injuries expert working group. Neonatal brain injuries in England: population-based incidence derived from routinely recorded clinical data held in the National Neonatal Research Database.

Increase in the use of inhaled nitric oxide in neonatal intensive care units in England: a retrospective population study

Drug utilisation in neonatal units in England and Wales: a national cohort study

Challenges of a simplified opt-out consent process in a neonatal randomised controlled trial: qualitative study of parents' and health professionals' views and experiences

The cost of Neonatal Abstinence Syndrome: an economic analysis of English national data held in the National Neonatal Research Database

Observational cohort study of changing trends in non-invasive ventilation in very preterm infants and associations with clinical outcomes

Changing clinical characteristics of infants treated for hypoxic-ischaemic encephalopathy in England, Wales and Scotland: a population-based study using the National Neonatal Research Database.

Early versus later initiation of parenteral nutrition for very preterm infants: a propensity score-matched observational study

Temporal trends of in utero and early postnatal transfer of extremely preterm infants between 2011 and 2016: a UK population study

Evaluating an enhanced quality improvement intervention in maternity units: PReCePT trial protocol

Anti-reflux medication use in preterm infants

International variations and trends in the treatment for retinopathy of prematurity

Management and outcomes of neonates with Down syndrome admitted to neonatal units

Variations in Neonatal Length of Stay of Babies Born Extremely Preterm: An International Comparison Between iNeo Networks

Feeding during neonatal therapeutic hypothermia: a retrospective population-based cohort study using routinely collected data held in the National Neonatal Research Database

Nutritional management in newborn babies receiving therapeutic hypothermia: two retrospective observational studies using propensity score matching

Contribution of de novo and inherited rare CNVs to very preterm birth

Randomised controlled trial of human derived breast milk fortifier versus bovine milk fortifier on body composition in very preterm babies

Outcomes of neonatal hypoxic-ischaemic encephalopathy in centres with and without active therapeutic hypothermia: a nationwide propensity score-matched analysis

Outcomes in relation to early parenteral nutrition use in preterm neonates born between 30 and 33 weeks gestation: a propensity score matched observational study.

Use of parenteral nutrition in the first postnatal week in England and Wales: an observational study using real-world data.

Management of patent ductus arteriosus in very preterm infants in England and Wales: a retrospective cohort study

Cervical ripening at home or in-hospital - prospective cohort study and process evaluation (CHOICE) study: Protocol

Kernicterus in neonates from ethnic minorities in the UK

Outcomes following the adoption of standard parenteral nutrition in preterm infants: a whole-population non-concurrent control study

Preterm Formula, Fortified or Unfortified Human Milk for Very Preterm Infants, the PREMFOOD Study: A Parallel Randomised Feasibility Trial

Place of birth and postnatal transfers in infants with congenital diaphragmatic hernia in England and Wales: a descriptive observational cohort study.

Clinical outcomes of Staphylococcus capitis isolation from neonates, England, 2015-2021: a retrospective case-control study

Risk factors for infection and outcomes in infants with neonatal encephalopathy: a cohort study.

Characteristics of children requiring admission to neonatal care and paediatric intensive care before the age of 2 years in England and Wales: a data linkage study

Studies

List of studies that have been conducted using the data source

DARWIN EU® - Use of antiretroviral therapies in paediatric patients

Data elements collected

The data source contains the following information

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

No

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

Yes

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

Yes

Cause of death

Captured

Cause of death vocabulary

Other

Cause of death vocabulary, other

Provided by EPR supplier

Prescriptions of medicines

Captured

Prescriptions vocabulary

other

Prescriptions vocabulary, other

Provided by EPR supplier

Dispensing of medicines

Not Captured

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Not Captured

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

Yes

Administration of vaccines

Yes

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

Provided by Clevermed Ltd EPR supplier

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available? The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

Yes

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays, infectious disease markers or metabolomic biomarkers.

Not Captured

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

No

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

No

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

Yes

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Other

Diagnosis / medical event vocabulary, other

Provided by Clevermed Ltd EPR supplier

Medicinal product information

Captured

Medicinal product information collected

Brand name

Medicinal product vocabulary

Other

If 'other,' what vocabulary is used?

Provided by EPR supplier

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Diet

Sociodemographic information

Captured

Sociodemographic information collected

Age
Deprivation index
Ethnicity
Gender
Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Estimated percentage of the population covered by the data source in the catchment area

All admissions to NHS neonatal units in England, Wales, Scotland and the Isle of Man.

Total population size by age (%):

100% of preterm newborn infants

10% term newborn infants

10% infants and toddlers

Active population size by age (%)

100% of preterm newborn infants

10% term newborn infants

10% infants and toddlers

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

Nation-wide capture of population in England, Wales, Scotland and the Isle of Man

Population

Population size

1300000

Active population size

10000

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

https://web.www.healthdatagateway.org/dataset/67020745-9def-4c6e-b5ac-bb273bd0a20e

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

No

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

Yes

Description of data collection

Data is collected using an Electronic Patient Record system. This data is then extracted from the EPR at quarterly intervals and curated to create the NNRD.

Event triggering registration

Event triggering registration of a person in the data source

Other

Event triggering registration of a person in the data source, other

Admission to neonatal unit in England, Wales, Scotland or Isle of Man.

Event triggering de-registration of a person in the data source

Other

Event triggering de-registration of a person in the data source, other

Parent request

Event triggering creation of a record in the data source

Admission to neonatal unit in England, Wales, Scotland or Isle of Man triggers admission record. Events that occur on the neonatal unit (daily care summary, drugs given, procedures and diagnoses) are then added to the admission record as and when they occur.

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

Yes

Linkage description, possible linkage

All data assuming linkage variables present

Linked data sources

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

Other NHS datasets (Hospital Episode Statistics, PICUNet etc)

Linkage strategy

Deterministic

Linkage variable

NHS Number, Date of birth and maternal postcode at time of birth

Linkage completeness

Completeness of linkages varies on the source that is being linked to

Data management specifications that apply for the data source

Data source refresh

Quarterly

Informed consent for use of data for research

Other

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

Data source preservation

Are records preserved in the data source indefinitely?

Yes

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Informed consent, other

There is a committee to evaluate requests for data access.

Data source last refresh

01/07/2022

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

Yes

CDM Mappings

CDM name

OMOP

CDM website

https://www.ohdsi.org/Data-standardization/

Data source ETL CDM version

5.3.1

Data source ETL frequency

3,00 months

Data source ETL status

Completed