# The UK National Neonatal Research Database: real-world data for real patient benefit

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UK Neonatal Collaborative

NDAU
Neonatal Data Analysis Unit

# Our goal



To harness the power of real-world clinical data to reduce uncertainties in clinical practice, and improve healthcare, health services and the life-long health of babies admitted to neonatal units

https://www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data-analysis-unit/

# NHS neonatal units



- Admit all sick and very preterm babies

- 200 neonatal units in England, Scotland, Wales, and Northern Ireland

- 80-100,000 patients admitted each year (10-15% of all UK births)

- Deliver care as Operational Clinical Networks

- Three levels of neonatal unit: Intensive Care; Local; Special Care

# National Neonatal Research Database

- An award-winning National Data Asset

- Established in 2007 though collaborative effort

- Based on the principle that clinical data should be recorded once and are a valuable resource to improve patient care in a variety of ways

- Contains a defined set of clinical data (the Neonatal Data Set, an approved NHS Information Standard) extracted at regular intervals from the electronic patient records of all admissions to neonatal units in England, Wales and Scotland (Northern Ireland set to join in 2022)

- Contains demographic data, daily treatments, procedures, diagnoses and outcomes, recorded throughout the in-patient stay
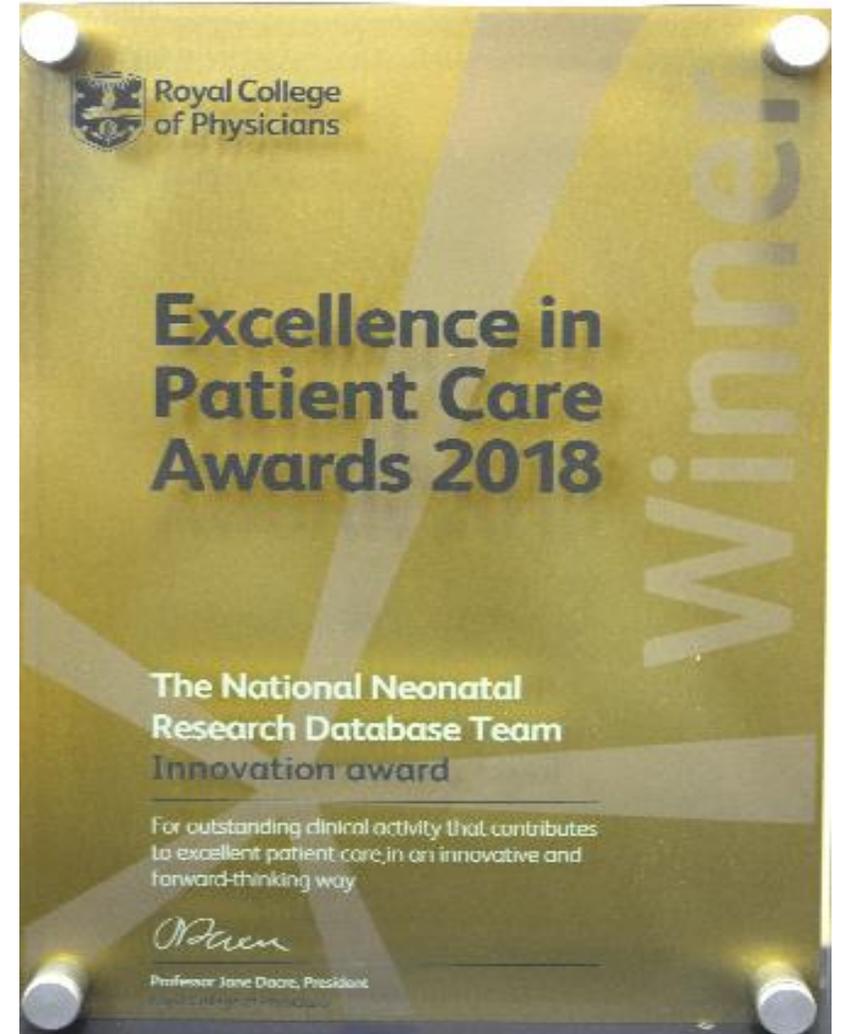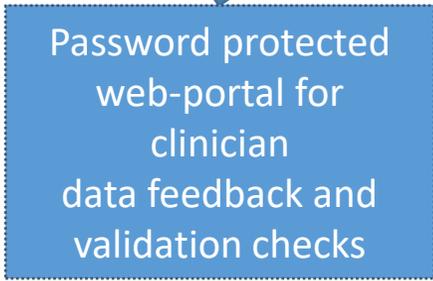
# The UK National Neonatal Research Database

## "If you cannot measure it, you cannot improve it"

- UK Research Ethics Committee approved dynamic, longitudinal database

- The basis of "cradle to grave" patient-level data

- Oversight by a steering committee with wide stakeholder representation, including parents

- To-date contains information on over a million infants and contributes to ~£28 million of funded research and research units

- Shows it is possible to replace labour-intensive, expensive collections with a single data source for multiple purposes, an approach now recommended for translation throughout the NHS

**Real-time data entry by clinical**  Neonatal Units  **staff throughout patient stay**

UK Neonatal Collaborative

Password protected web-portal for clinician data feedback and validation checks
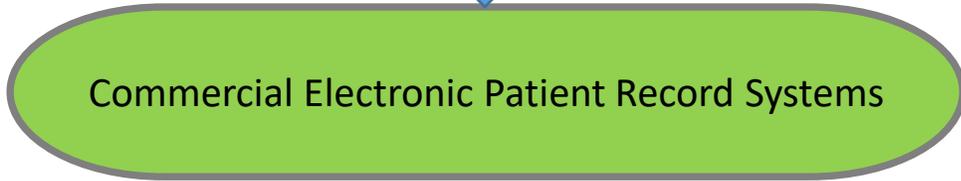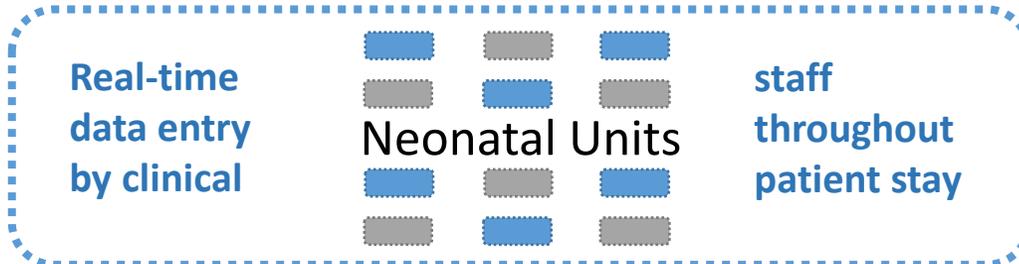
**The Neonatal Data Set: a bespoke NHS Information Standard**  NHS Digital
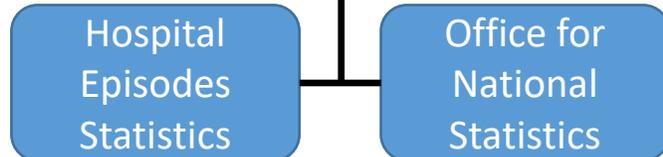
Commercial Electronic Patient Record Systems

**Extraction of Neonatal Data Set with quality assurance and curation to create the NNRD**

National Neonatal Research Database
Imperial College London
Established 2007; to-date contains data on over 1 million infants; 100000 new patients added annually

**Multi-Professional Neonatal Data Analysis Unit Steering Board with parent involvement**

**Comprehensive regulatory approvals**

**Linkage to form a cradle-to-grave record**

Hospital Episodes Statistics

Office for National Statistics

RCPCH — National audit

BMJ FN / THE LANCET Gastroenterology & Hepatology / JAMA Pediatrics — Health services and clinical research

Quality improvement

Department of Health / NSC UK National Screening Committee — Commissioning support

Surveillance

National reporting

INC CRITICAL PATH INSTITUTE — Outcomes evaluation

Royal College of Obstetricians & Gynaecologists — Benchmarking

**Multiple outputs**

# NNRD contributions to patient benefit

## Health services

- High-profile NHS maternity investigations (e.g. Morecambe Bay 2015; East Sussex 2018)

- Improved preterm outcomes in high volume neonatal units (BMJ Open 2014), with 1:1 nursing care (Arch Dis Child 2016), and following a national neonatal services reorganisation into managed clinical networks (BMJ 2012)

- Reduced preterm mortality and severe brain injury with birth in specialised hospitals (BMJ 2019)

- Measurement of adherence to care standards (National Audit Programmes; from 2007)

## National policy

- Department of Health quantification of neonatal brain injuries over time (from 2017)

- Data to support the introduction of enhanced parental leave for parents of babies requiring intensive care (2019)

## Health care

- US Food and Drug Administration study to support newborn medicines development (current)

- Largest global study (90,000 infants) of preterm weight gain facilitating improved growth monitoring (Lancet Child Adolesc Health 2021)

- Identification of best feeding practice for babies with brain injury (Lancet Child Adolesc Health 2021)

- Fall in very preterm admissions among most deprived socio-economic groups during COVID lockdown (BMJ Open 2021)

- North-south England variation in preterm mortality (Arch Dis Child 2017)

- Protection against necrotising enterocolitis from early feeding with own mothers' milk (Lancet Gastroenterol Hepatol 2017)

- The Health Data Research Hub for Real World Evidence in the UK
- One of seven pioneering UK data hubs



- First European March of Dimes Prematurity Research Centre, joining five in the US



- Department of Health funded Maternal and Neonatal Policy Research Unit

# Ongoing and planned developments

- **NNRD-AI**: state-of-the-art data curation for data science, AI and machine learning applications

- **NNRD-DigitalTwin**: a version containing synthetic data for use without patient confidentiality issues

- **NNRD-Clinical Trials**: data-enabled, efficient, cost-effective, rapid, randomised controlled trials

- Linkage to other datasets: e.g. maternity data (Mother and Baby Data Hub)

- Linkage to sample collections: e.g. genomic data, and incorporation of physiological monitoring, imaging and laboratory data

- Consent-to-contact register (to improve access to research)

- **NNRD-Preterm**: One of the world's largest longitudinal preterm birth cohorts

# eNewborn

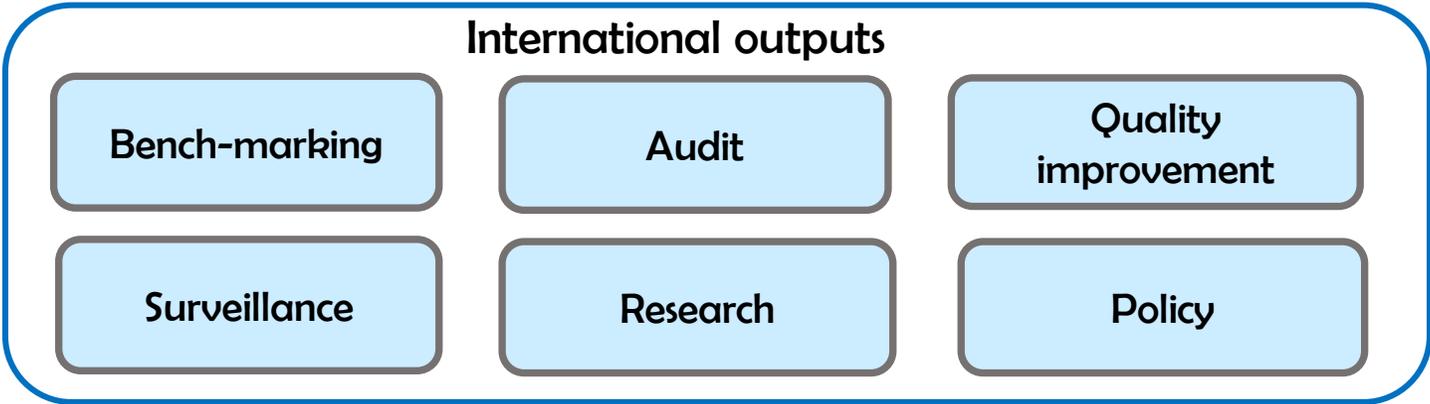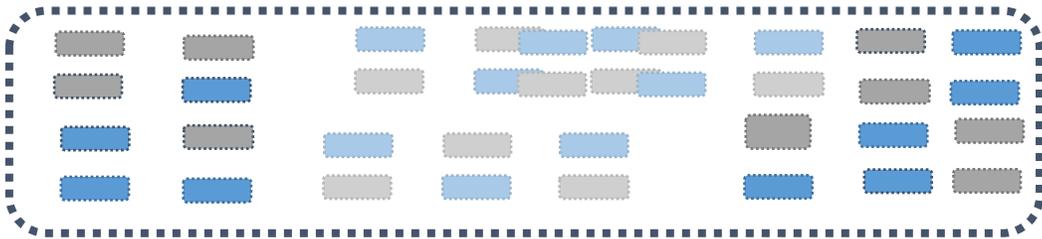# an International Neonatal Research Database

https://www.imperial.ac.uk/neonatal-data-analysis-unit/enewborn/

For more information, please go to our website or email enewborn@imperial.ac.uk

# eNewborn

Neonatal units in the UK

Neonatal units across the world

Quality improvement studies → Audit → Quantification of variation in outcomes → Observational studies → Clinical trials → Health services research → Epidemiological research → Safety monitoring → Quality improvement studies

## Impacts

- Multiple benefits across the patient benefit pathway
- Strong public-patient trust in health data research

## Opportunities

- Linkage to health and non-health datasets
- Technical data-handling advances
- International collaboration

## Challenges

- Fragmented NHS (across providers and 4 nations)
- NHS-research divide (regulatory and operational)
- Infrastructure and development resourcing

# Accessing the National Neonatal Research Database through the Health Data Research UK Gateway

# With thanks to

➤ The UK Neonatal Collaborative

➤ Our patients and their families

➤ My wonderful research group

➤ The National Neonatal Research Database Steering Board

| | |
|---|---|
| Co-chairs | Professors Andrew Wilkinson and Kate Costeloe |
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Professor Andrew Wilkinson