Using data to improve UK neonatal care: past, present and future

The article summarises the progress of the neonatal data landscape in the UK over the last 25 years, with particular reference to progress and achievements over the last decade. We have outlined the four main challenges faced by the current neonatal data landscape in the UK, including the need for single entry of correct and relevant data that flow to one national neonatal database; interoperability between electronic patient record systems; consistencies in quality measures; improved access to data for relevant persons and/or bodies. We have also provided our vision for the future, calling for closer collaborative working and training resources to raise awareness of the UK neonatal data landscape.

Tng Chang Kwok
Neonatal Grid Trainee and Research Fellow, University of Nottingham

Cheryl Battersby
Neonatal Consultant and Clinical Senior Lecturer in Neonatal Medicine, Imperial College London
c.battersby@imperial.ac.uk

On behalf of the British Association of Perinatal Medicine Data and Informatics Steering Group

Keywords

neonatal data; challenges; future

Key points

Kwok T.C., Battersby C. Using data to improve UK neonatal care: past, present and future. *Infant* 2022; 19(2): 54-59.

1. The UK neonatal data landscape is an exemplar for other specialties with both a national data capture and an Information Standards Board approved neonatal dataset.
2. The BAPM Data and Informatics Group identified four main challenges to overcome to safeguard current and future advancements.
3. Closer collaborative working and resources to facilitate increased awareness of the current neonatal data landscape are needed to be able to properly harness the power of population-scale data to improve neonatal care.

The BAPM Data and Informatics Group

The British Association of Perinatal Medicine (BAPM) Data and Informatics Steering Group welcomes the Royal College of Paediatrics and Child Health (RCPCH) strategy, which includes *'Harnessing knowledge, data and intelligence to improve the quality of care for children and young people'* specifically *'Using data to identify gaps and explore deficiencies in child health and services'*.[1]

The neonatal community has long recognised the importance of data including the concept of reducing data burden for clinicians by capturing data once for a variety of purposes. Often referred to as an exemplar for other specialties the neonatal community has, over the past decade, achieved national data capture and an Information Standards Board approved neonatal dataset.[2] These data have afforded valuable opportunities to inform improvements in neonatal care through national audit, quality improvement, service evaluation and research. However, there are concerns over the increasing complexity of neonatal data resulting from reporting demands from a range of organisations, conflicting quality measures and definitions, and multiplicity of electronic patient record (EPR) systems hampering interoperability.

In January 2021, BAPM convened a Data and Informatics Group to understand and address these concerns. The group comprises a small steering group with representation from multidisciplinary professionals and parents/patients, and a larger stakeholder group with representation from UK organisations and regions.[3] Through a series of meetings, the group agreed that its remits are to:

FIGURE 1 The BAPM data group remit.

1. advocate for collection and use of accurate perinatal data for audit, research, service evaluation, commissioning, quality improvement and benchmarking to benefit babies and their families
2. promote standardisation of quality measures and interoperability of EPR systems to avoid unnecessary duplication and burden for those inputting the data

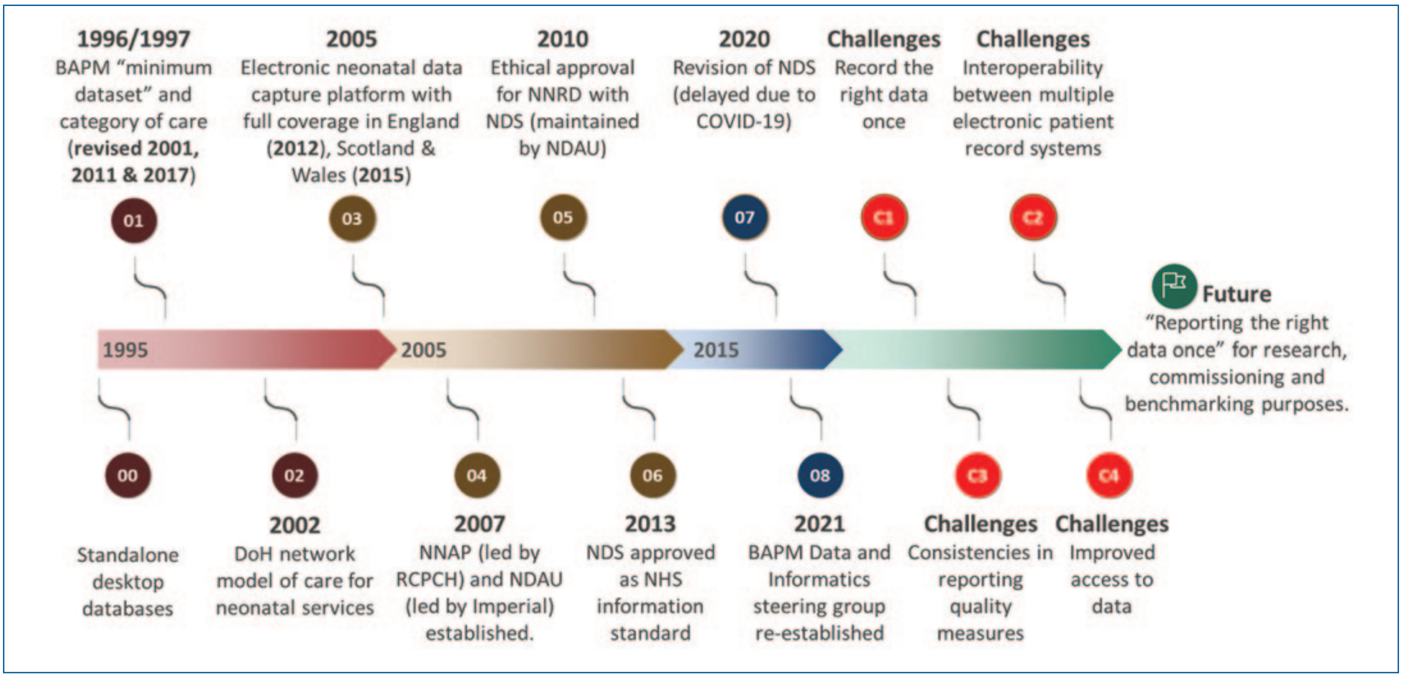

FIGURE 2 Timeline depicting the neonatal data landscape over the last 25 years and proposed future aim and challenges. Key: BAPM=British Association of Perinatal Medicine; DoH=Department of Health; NNAP=National Neonatal Audit Programme; RCPCH=Royal College of Paediatrics and Child Health; NDAU=Neonatal Data Analysis Unit; NNRD=National Neonatal Research Database; NDS=Neonatal Dataset.

3. facilitate collaboration and closer working between stakeholders to streamline data collection and analysis for common purposes
4. develop and share resources that will help support perinatal professionals to maximise the utility of data to benefit patient care.

This article aims to highlight progress and achievements over the last decade and to outline what is required to safeguard and future proof the continuation of national data-driven improvements in neonatal care.

Successes in the last decade

Electronic neonatal data capture

EPRs were introduced from 2005, driven by the reorganisation of neonatal services into managed clinical networks and the need to share information for babies transferred between neonatal units. Over the next decade, a growing number of neonatal units adopted the neonatal-specific platform BadgerNet Neonatal Summary system, developed by an NHS-approved commercial company (**FIGURE 2**).[4]

Development of national neonatal datasets and a repository for national data

BAPM has long recognised the need for consistent data collection and first developed a minimum neonatal dataset in 1997, primarily to define daily levels of care. In 2007, a group of academic investigators, a network manager and a national charity representing parents established the Neonatal Data Analysis Unit (NDAU) with the aim of using standardised neonatal data for health services support, evaluation, surveillance, audit and research. In 2010, National Research Ethics approval was granted for the NDAU to curate and maintain a National Neonatal Research Database (NNRD), which would contain the national Neonatal Dataset (NDS) incorporating the Neonatal Critical Care Minimum Dataset (NCCMDS) (**FIGURE 2**).

The NCCMDS was developed to facilitate the National Tariff Payment System (NTPS) within neonatal critical care. It supports the NTPS by using data captured to generate a Neonatal Critical Care Healthcare Resource Group (HRG) for each calendar day of a period of neonatal critical care,[5] which have been used to define neonatal activity-based income for services. BAPM developed categories of care in 1996 to enable reporting of neonatal care activity by intensive, high dependency and special care days; these were revised in 2001 and 2011,[6] with an HRG update in 2016.

The NDS outlines nearly 400 data variables in the NNRD, including patient demographics, clinical interventions, diagnoses and outcomes.[2] The NNRD includes data for all admissions to NHS neonatal units in England, Wales and Scotland since 2012. At present, the NNRD contains information on around one million babies and 10 million days of care, with approximately 25,000 new patients added each quarter. Researchers, clinicians, managers, commissioners, and others are able to utilise the NNRD and details of how to access it are available.[7]

One of the important milestones was having both the NDS (ISB 1595) and NCCMDS (SCCI0075) approved as information standards in 2013.[2,5] The Data Alliance Partnership Board (DAPB) (previously the Data Coordination Board) oversees this rigorous approval process and assures the quality of information standards.[8] Key advantages of having an Information Standards Board approved dataset include consistency in data variables and definitions, and facilitating the creation of a single national repository of data, such as the NNRD that can be used for multiple purposes. Importantly, the emphasis is based on the data item or variable rather than the EPR system. All EPR contractors or suppliers are expected to comply with data specifications set out in the Information Standards Notice.

The NCCMDS is currently maintained by the National Casemix Office within NHS Digital and the NDS is maintained by the NDAU, based at the Chelsea and Westminster Hospital Campus of Imperial College London.[9] The NDS was last reviewed in 2022.

Stakeholder	Start year	Aims/remit	Data source/ population	Funding source	Main outputs
NNAP[14]	2007	The NNAP's overarching quality improvement objectives are to: • reduce unit and network level variation • to seek to reach agreed developmental standards for process measures nationally • report outcome measures and their variation between units and networks	2006-2019: NNRD 2020: Clevermed BadgerNet All admissions to neonatal units in England, Wales, Scotland	Commissioned by HQIP, delivered by RCPCH. Funded by England, Scottish, Welsh governments	Annual NNAP report 'Near realtime' reporting of quality measures Quarterly data quality reporting
NDAU[9]	2007	To support audit, evaluations, bench-marking, quality improvement and clinical, epidemiological, health services and policy research to improve patient care and outcomes	NNRD All admissions to neonatal units in England, Wales, Scotland	Grant income	Health services evaluation Research publications
ODNs[16]	2004 with revisions to format and structure in 2013	Identify and monitor strategic aims, align service development to national and local priorities and ensure identification of future needs to maintain and improve patient access and equity of service delivery to the required standards	Predominantly Clevermed BadgerNet Providers in network	NHS England Specialised Commissioning	Network reports and 'dashboards'
Neonatal Critical Care Clinical Reference Group[17]	2013	CRGs provide clinical advice and leadership for specialised services offering specific know-ledge and expertise to advise on the ways that specialised services should be provided Lead on the development of clinical commissioning policies, service specifications and quality standards	Various England	NHS England Specialised Commissioning	Commissioning products Specialised Services Quality Dashboards
GIRFT[18]		To support providers in delivering service and efficiency improvements through identification of areas of unwarranted variation in clinical practice and/or divergence from the best evidence	NHS Digital, BadgerNet, MBRRACE UK, NNAP, GIRFT, questionnaires England	NHS England/ Improvement	Individual trust and network datapacks National reports: GIRFT National Neonatology and Neonatology Workforce Reports
NCMD[19]		Statutory reporting and recording of comprehensive data, standardised across a whole country (England), on the circumstances of children's deaths Aims to reduce modifiable child mortality	Child Death Review partners and Child Death Overview panels England	HQIP on behalf of NHS England	Annual data report for England Real-time surveillance reports for NHS England
MBRRACE-UK[20]	2012	To provide robust data and evidence to support: • improving the quality of maternity and neonatal care • reducing inequalities in maternal and perinatal outcomes • education, training and continuing professional development of clinical staff	Perinatal deaths data from all trust and health boards across the UK. Births and deaths data from ONS, NHS Digital, NRS, NIMATS	NHS England, Scottish, Welsh and Northern Ireland governments. Commissioned on behalf of the funders by HQIP	Perinatal mortality surveillance, confidential enquiries, annual reports and interactive maps Real-time data monitoring tool
PMRT	2017	A tool to support systematic, robust, local review of all perinatal deaths It is not a data collection tool as such, but the process inevitably 'collects' data	Reviews of perinatal deaths carried out in local trusts/health boards England, Wales, Northern Ireland, Scotland, Jersey, Guernsey, Isle of Man	DHSC England, Scottish, Welsh and Northern Ireland governments. Commissioned by HQIP on behalf of the funders	National report published with the higher level findings

(TABLE 1 continues on next page...)

(...TABLE 1 continued)

Stakeholder	Start year	Aims/remit	Data source/ population	Funding source	Main outputs
NMPA[21]	2017	To produce accessible and relevant outputs on a number of key measures and to identify unexpected variation between maternity services	NNRD NHS Digital (Maternity Services Data Set) England, Scotland and Wales	Commissioned by HQIP and led by the RCOG in partnership with RCM, RCPCH and LSHTM	Quarterly report of clinical data, annual report and periodic 'sprint audits' Research publications
Reference cost data / National Cost Collection	Since 1980s	To provide benchmark costs for neonatal care via the five specialist neonatal Health Group Resources	Trust direct data submission to NHS Digital/National Casemix Office England	NHS Digital/ National Casemix Office	Annual open access publication via NHS Digital
NIB	2019	Established to provide oversight for ensuring implementation of the actions from the Neonatal Critical Care Review	BadgerNet data currently via ODNs England	NHS England/ Improvement	Quarterly information
Secondary Uses Service		The Secondary Uses Service is the single, comprehensive repository for healthcare data in England, which enables a range of reporting and analyses to support the NHS	Direct from Trusts (most commonly via BadgerNet) England	NHS England/ Improvement	Healthcare planning, policy development, commissioning, National Tariff reimbursement
NHS England Specialised Commissioning	A national body within NHS England since 2013, with both national and regional teams	Commissioner and accountable organisation for specialised services including: specialised maternity services, neonatal critical care, specialised paediatric services, including surgery and critical care	Secondary Uses Service and reference cost data England	HM Government, via Secretary of State for Health and Social Care	Commissioning Accountable organisation for specialised services

TABLE 1 Stakeholders. Key: NNRD=National Neonatal Research Database; ODN=operational delivery network; HQIP=Healthcare Quality Improvement Partnership; RCPCH=Royal College of Paediatrics and Child Health; NDAU=Neonatal Data Analysis Unit; CRG=Clinical Reference Group; GIRFT=Getting It Right First Time; MBRRACE-UK=Mother and babies - reducing risk through audits and confidential enquiries across the UK; NCMD=National Child Mortality Database; ONS=Office for National Statistics; NRS=National Records of Scotland; NIMATS=Northern Ireland Maternity System; PMRT=Perinatal Mortality Review Tool; DHSC=Department of Health and Social Care; NMPA=National Maternity and Perinatal Audit; RCOG=Royal College of Obstetricians and Gynaecologists; RCM=Royal College of Midwives; LSHTM=London School of Hygiene and Tropical Medicine; NIB=Neonatal Implementation Board.

Measuring high quality neonatal care

"Measurement is essential for improvement" Lord Darzi.[10]

Interest in data has grown hugely over the last decade. The need to deliver high quality 'value for money health care' has necessitated the measurement, monitoring and comparison of processes and outcomes against set standards and targets. These standards are set by various organisations including the National Institute for Clinical Excellence (NICE) and government (eg the NHS Long term plan,[11] Healthcare Quality Strategy for NHS Scotland[12] and Quality Standards for Health and Social Care[13]), and are drivers for local, network and national audits and benchmarking.

The National Neonatal Audit Programme (NNAP) was established in 2006 and commissioned by the Healthcare Quality Improvement Partnership (HQIP) to assess whether babies admitted to neonatal units in England, Scotland and Wales receive consistent high quality care.[14] The NNAP is funded by NHS England and the Scottish and Welsh governments and currently delivered by the RCPCH. The NNAP looks at around 10-15 areas of care provided to babies born preterm or unwell; this includes measures focussing on processes, outcomes and parental involvement in care.[15] The NNAP has been an important driver for better neonatal data completeness and accuracy as well as improved quality of care.

What is needed?

Having listened to the neonatal community and a wide group of stakeholders, BAPM supports the following:

- single entry of correct and relevant data that flow to one national neonatal database
- interoperability between EPR systems
- consistencies in quality measures
- improved access to data.

Record the right data once

Over the last decade, the neonatal community has embraced and championed the ethos of 'recording the right data once' and using it for multiple purposes. The data needed for high quality research are the same data necessary for commissioning, audit and service evaluation. A number of other organisations have harnessed these data to drive improvements in patient care at a population level (**TABLE 1**). Recording data once avoids unnecessary burden on busy clinical teams and reduces errors and inconsistencies resulting from multiple entry. Lack of interoperability between EPR systems threatens the paradigm the neonatal community has successfully fostered.

Interoperability between multiple EPR systems

Over the last decade, having a common national electronic neonatal platform supported by a single commercial supplier has facilitated the ease of data transfer between hospitals to benefit patient care. Over the last few years, a growing number of different hospital wide EPR systems have been implemented around the country. While we recognise the financial and technical complexities of commissioning EPRs, it is essential that EPRs are able to 'speak to each other'. Specifically, lack of interoperability between EPR systems must not result in multiple EPR systems running in parallel, eg to permit sharing data between hospitals. The latter is of paramount importance since UK neonatal care is delivered in a network model and commonly involves transfer of babies between different neonatal units. The risk of trust-wide digital solutions that are not appropriate for neonatal care or unable to support national neonatal data reporting must be considered if/when changes to EPR systems are contemplated and with this in mind, the BAPM Data and Informatics Group has convened a smaller working group to develop a service specification for neonatal data requirements. Chaired by Dr Giles Kendall, the working group aims to develop a service specification toolkit by autumn 2023 to support conversations between neonatal clinical and hospital procurement teams who are in the process of EPR procurement (further information can be found at www.bapm.org/pages/data).

Consistencies in reporting quality measures

Neonatal units share data with a number of stakeholders for benchmarking, audit, research and commissioning at local, national and international levels (**TABLE 1**). Understandably, each stakeholder has a slightly different focus and there is growing concern that this may lead to inconsistency in reporting measures and create unnecessary additional burden on neonatal teams inputting data. **TABLE 2** contains examples of different reporting definitions for similar measures. The Neonatal Critical Care Review call for a review of capacity across neonatal services as well as improvements in standards will require consistent national as well as local data to ensure appropriate comparison(s).

The number of potential quality measures for neonatal care is vast and clinical input is required to ensure that the measures chosen have clinician buy-in. Achieving consensus in relation to definitions and measures is difficult and requires leadership from knowledgeable, professional organisations, including BAPM and RCPCH.

Improved access to data at local, network and national levels

Alongside these quality measures, demographic and activity data are also essential. Neonatal networks have a mandate to develop and implement programmes of work to improve access to specialist resources and to improve neonatal outcomes and patient experience, working closely with both providers and commissioners. Good quality data are also required for research to inform future practice. Within the necessary constraints of patient confidentiality and data ownership, we need to work together to ensure that relevant neonatal data are easily accessible to appropriate persons/organisations and used for multiple purposes.

Close collaborative working

We believe that the above needs can be met with closer collaborative working between stakeholders, hospital trusts, the neonatal community, neonatal networks, commissioning teams and commercial

	NNAP	MatNeoSIP	NMPA	BAPM Quality Toolkit	NHS England/SSQD/NIB
Antenatal steroids	23-33 weeks Any dose Any time Reported on month of discharge	24^{+0}-33^{+6} Complete course within 7 days reported on month of birth	NR	<34 weeks >24hrs and complete course <7 days before birth	NR
Term admissions/ minimising mother/baby separation	$\geq 37^{+0}$ All care in one unit Admitted for minimum 12hrs No surgery No added O_2 or respiratory support	NR	37^{+0}-42^{+6} singletons	NR	$\geq 37^{+0}$ (ATAIN) – all babies admitted to a NNU
Delayed/ deferred cord clamping	Does a baby born at less than 32 weeks' gestation have their cord clamped at or after one minute?	Proportion of babies <34 weeks who received delayed cord clamping/ cord stripping at the time of delivery	NR	Optimal cord management in all preterm babies less than 34 weeks' gestation (defined by waiting at least 60 seconds before clamping the umbilical cord)	NR

TABLE 2 Inconsistencies: examples of different definitions for similar reporting measures. Key: NR=not reported; MatNeoSIP=Maternity and Neonatal Safety Improvement Programme; SSQD=Specialised Services Quality Dashboard; ATAIN= Avoiding Term Admissions into Neonatal units programme.

EPR suppliers. For example, we need to work together to find a national solution that enables different EPR systems to communicate effectively with each other. A potential solution is a national data warehouse that captures all required datasets from EPR systems in a standards compliant fashion. Such a database should allow EPR systems to pull data and act as a ‘single patient record’ for clinically critical data, thus permitting reporting at trust, network and national level to support both service design and quality improvement.

Future opportunities

Going forward, the neonatal community must continue to harness the power of population-scale data to improve neonatal care. There should be nationally agreed plans to develop data interrogation tools to facilitate more inclusive use of national data including other childhood health, education and maternity datasets to be able to interrogate outcomes over the life course. With a much more data-aware generation of perinatal professionals, BAPM strongly supports the promotion of an even deeper understanding of the importance of neonatal data and the potential to inform improvements in neonatal care. With a commitment to the development and delivery of national training resources, this article is the first step in raising awareness of the current neonatal data landscape. An electronic version of neonatal data frequently asked questions can be accessed on the BAPM website at www.bapm.org/pages/data-faqs.

Acknowledgement

The BAPM Data and Informatics Steering Group members are: Dr Cheryl Battersby (Chair), Charlotte Bradford, Dr Sanjeev Deshpande, Dr T’ng Chang Kwok, Juliette Lee, Dr Helen Mactier (2019-2022), Dr Sajit Nedungadi, Dr Stephen Wardle (BAPM Honorary Secretary, Chair BAPM Data Stakeholder Meeting), Louise Weaver-Lowe, Kirstin Webster.

The authors would also like to thank all the stakeholders within the BAPM Data and Informatics Stakeholder Group for their contribution and input to this article, especially in **TABLE 1**: Dr Eleri Adams (Getting It Right First Time), Sally Cavendish (NHS England Specialised Commissioning), Dr Ngozi Edi-Osagie (Neonatal Critical Care Clinical Reference Group), Daniel Eve (NHS England), Professor Jenny Kurinczuk (Mother and Babies - Reducing risk through audits and confidential enquiries across the UK), Professor Karen Luyt (National Child Mortality Database), Dr David Millar (Representative for Northern Ireland), Professor Neena Modi (National Neonatal Research Database), Professor Sam Oddie (Royal College of Paediatrics and Child Health), Dr Colin Peters (Representative for Scotland), Dr Oliver Rackham (Representative for Wales), Kirstin Webster (National Maternity Audit Programme) and Rachel Winch (National Neonatal Audit Programme).

References

1. **Royal College of Paediatrics and Child Health.** Strategy 2021-24. 2021 online at: www.rcpch.ac.uk/sites/default/files/2021-09/Full%20RCPCH% 20 College%20strategy%202021-24%20-%20web.pdf
2. **NHS Digital.** Neonatal data set 2014. Online at: https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dapb1595-neonatal-data-set
3. **BAPM.** BAPM Data and Informatics Steering Group. 2021 online at: www.bapm.org/pages/bapm-data-and-informatics-steering-group
4. **Clevermed**. Clevermed Badgernet. 2021 online at: www.clevermed.com
5. **NHS Digital.** Neonatal Critical Care Minimum Dataset. 2016 online at: https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci0075-neonatal-critical-care-minimum-data-set-version-2
6. **BAPM.** Categories of care: A BAPM framework for practice. 2011 online at: www.bapm.org/resources/34-categories-of-care-2011
7. **Neonatal Data Analysis Unit.** Utilising the National Neonatal Research Database 2021 online at: www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data-analysis-unit/utilising-the-nnrd/
8. **NHS Digital.** Information standards and data collections. 2021 online at: https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/data-alliance-partnership-board
9. **Imperial College London.** Neonatal Data Analysis Unit. 2021 online at: www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data-analysis-unit
10. **Kmietowicz Z.** Darzi review: Annual 'quality accounts' will help improve services and increase choice for patients, says Lord Darzi. BMJ 2008;337:a646.
11. **NHS England.** NHS Long Term Plan. 2019 online at: www.longtermplan.nhs.uk
12. **NHS Scotland.** The Healthcare Quality Strategy for NHS Scotland. 2010 online at: www.gov.scot/publications/healthcare-quality-strategy-nhsscotland/
13. **Department of Health,** Social Services and Public Safety Northern Ireland. Quality Standards for Health and Social Care. 2006 online at: www.health-ni.gov.uk/sites/default/files/publications/dhssps/the-quality-standards-for-health-and-social-care.pdf
14. **RCPCH.** National Neonatal Audit Programme. 2021 online at: www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/national-neonatal-audit-programme
15. **National Neonatal Audit Programme.** NNAP: A guide to the 2020 audit measures. 2019 online at: www.rcpch.ac.uk/work-we-do/clinical-audits/nnap
16. **NHS England.** Operational delivery networks. 2021 online at: www.england.nhs.uk/ourwork/part-rel/odn
17. **NHS England.** Neonatal Critical Care Clinical Reference Group. 2021 online at: www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e08
18. **Getting It Right First Time.** Online at: https://gettingitrightfirsttime.co.uk/medical_specialties/neonatology/
19. **National Child Mortality Database.** Online at: www.ncmd.info
20. **National Perinatal Epidemiology Unit.** Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK). Online at: www.npeu.ox.ac.uk/mbrrace-uk
21. **National Maternity and Perinatal Audit.** Online at: https://maternityaudit.org.uk/pages/home