# Database development, monitoring and improvements in neonatal outcome

Health care requires the collection and use of data, whether on paper or in an electronic record. Apart from direct clinical care, there are many secondary uses of data that are important for funding, monitoring quality, audit and research. This article describes why all involved in health care must be involved in the use of data and how this can be used to improve quality of care and hopefully outcome for the newborn baby.

#### Andrew Lyon

MA, MB, FRCP, FRCPCH Retired Consultant Neonatologist Simpson Centre for Reproductive Health Royal Infirmary of Edinburgh andy.lyon@clevermed.com

# Keywords

neonatal care; electronic patient record; secondary use of data

# Key points

**Lyon A.** Database development, monitoring and improvements in neonatal outcome. *Infant* 2013; 9(3): 98-101.

- 1. All staff involved in clinical care of the newborn have a responsibility to collect and use data.
- 2. Trusts should provide appropriate resources for data collection and analysis.
- 3. A single electronic patient clinical record, linked across the N3 network, allows the collection of once-only standardised data.
- All units must contribute to national benchmarking that is linked to appropriate clinical improvement programmes.

The collection and use of data are integral to the care of patients. The clinical record is of primary importance and is vital for the ongoing management of a patient. There are, however, many other important reasons why all involved in health care must be involved in the collection and use of data.

# Why collect data?

Providing quality care is a core principle of modern health care. A definition of quality is doing 'the right thing, at the right time, in the right way, for the right person – and having the best possible results'<sup>1</sup>. This means that healthcare providers have a duty to examine their practice and, where appropriate, implement change. This can only be achieved by using data collected during the process of health care. There is no single measure of quality. Effectiveness, access and timeliness, capacity, safety, patient-centredness and equity are key domains that are used to evaluate and monitor quality of health care<sup>2</sup>.

These areas of quality measurement have been included in the UK Department of Health (DH) Toolkit for High Quality Neonatal Services<sup>3</sup>. There are eight principles covering the major areas of activity within the neonatal care pathway, with data collection highlighted as an essential part of the service. The Toolkit gives examples of the metrics that should be measured; the data being used to monitor service structure, service process, health outcomes and network outcomes. There is a requirement for Trusts to support the clinical team in collecting and using data to monitor quality through use of the toolkit.

The British Association of Perinatal Medicine (BAPM) has published standards for hospitals involved in the care of the newborn baby<sup>4</sup>. Units must comply with the principles set out in the DH Toolkit. Data collection is, again, highlighted as essential for monitoring quality and performance standards.

Since 2003, neonatal care in England has been organised in networks and a similar model is being developed throughout the UK. Each network has its own protocols for optimum management of the sick newborn baby, with an appropriate division of work between intensive care units, local neonatal units and special care nurseries. The National Audit Office report published in 20075, found that this reorganisation had improved the coordination, effectiveness and consistency of services. However, the report concludes that: 'The lack of robust evidence on outcomes makes it difficult to reach an objective view of the quality of the service'. Among the recommendations, was the need to improve the collection of data and use of information to establish the efficiency and effectiveness of the service, particularly in calculating the long-term impacts of different types of care. It was recommended that all units, as a priority, contribute fully to the National Neonatal Audit Programme (NNAP) minimum dataset. It was also recommended that network managers work with units to reduce duplication of data collection.

All budgets are under increasing pressure. The use of data to justify and monitor funding is now a vital function of all Trusts. Staffing levels need to be linked directly to intensity of workload. BAPM has published definitions of levels of care that are directly related to staffing requirements and the calculation of these requires daily collection of a large dataset. In England and Wales, funding is based on 'payment by results' requiring the calculation of daily healthcare related groups (HRG) for all babies. This is achieved using the Neonatal Critical Care Minimal Dataset (NCCMDS) which, although similar, has differences to that used to calculate BAPM care levels.

Commissioning of neonatal services is changing, with a move from Specialised Commissioning Groups to core responsibility of the NHS Commissioning Board. A quality assurance process will be linked to the NHS Outcome Framework. A Neonatal Clinical Reference Group will provide fixed objective and performance measures that can be beneficial for providers, commissioners and users to assess progress towards quality standards. Commissioners and the public have a right to know that a service is not only well run, with good quality care and outcomes, but also that it is efficient and not wasting money.

Resources for data collection are expensive and, for purposes other than direct patient care, there is often a perception that data collection detracts from the care of the baby. However, what is clear is that everyone associated with the care of the newborn has a duty to be involved in the collection and use of data, not only for direct patient care but for the monitoring of quality and efficiency of the service. It is no longer acceptable to assume that good care is delivered; this must be demonstrated by showing adherence to various quality measures. Ongoing funding of a service depends on showing that quality standards are achieved. Requests for extra resources will only succeed if supported by strong data showing how quality outcomes and efficiency can be improved.

## How are data collected?

Paper-based clinical records vary in quality and completeness. However, free text notes are often the best way of capturing the clinical picture as well as the opinions of those involved in the care of the baby. Where there are large volumes of notes, finding information can be difficult and extraction of data for use in quality monitoring, audit and research is time consuming and involves duplication of effort. Electronic records make searching and summarisation of data easier, helping to inform clinical staff. Data entry can be slower than with paper notes, especially if free text is used extensively. However, the power of electronic systems is their ability to collect standardised data that can be easily extracted for multiple purposes.

Interfaces with other hospital systems, such as maternity and laboratory services, reduce duplication of entries and improve the quality of data available to the clinical team. Linking with child health systems not only improves clinical care, but also allows analysis of long-term outcomes. Software systems must be able to communicate with each other through appropriate industry-standard messaging.

Electronic systems must help improve care by directing staff with important reminders and checks. Users can be alerted that data essential for important datasets – such as those used for funding, quality monitoring or research – have missing items. In this way, these systems improve clinical care, data quality and completeness<sup>6</sup>.

Many units contribute to datasets collected separately to that used in clinical care. Examples include the Trent Neonatal Survey, where funded nurses gather the data from the clinical notes, and the Vermont Oxford Network (VON) database, which relies on units to collect and submit a specific dataset. In these cases, the quality and completeness of the data are good because few people are involved in collection, the rules are very specific and the users are experienced in the definitions of the data items. However, the cost and resource implications are major.

The alternative is to analyse data that have been collected routinely at the time of clinical care. This avoids duplication and demand on resources but, because there are many users of varying experience entering data, there are frequent problems with quality and completeness. Systems can help with checks and reminders but there remains much variation in quality. However, routinely collected data have been found to be accurate in assessing some population-based statistics<sup>7</sup>.

Replacing all paper with an electronic system is expensive in terms of both software and hardware. Ease of use at the bedside is important, but may require a large investment in infrastructure to accommodate the technology. In neonatal

care, full electronic medical records tend to be used in larger intensive care units. Experience across the UK has shown that the combination of paper with an electronic clinical summary system works effectively. Because electronic data is easy to use, there is a tendency to keep expanding the dataset collected. However, staff may not see any advantage in this as the system does not save them time (in terms of data entry) and they do not perceive any advantage over paper records. It is important that users understand why all data items are collected, particularly if these are not directly related to patient care. Completeness and quality can only be achieved if all items are well defined (avoiding ambiguity in what needs to be collected) and staff 'buy in' to data collection.

The N3 Network (NHS Internet Gateway, NHS net) is a secure, national, high-speed, broadband network that has allowed the secure sharing of clinical information across the UK. Many babies are transferred to other units during a period of neonatal care – the ability to share a single clinical record improves quality of care as well as allowing the collection of a standardised dataset that can be used for national benchmarking and analysis of outcomes.

The Badger Neonatal Clinical Information System (BadgerNet, Clevermed Ltd) is used by neonatal units across the UK. It comprises a single patient record on the N3 network that includes all neonatal and transport episodes of care. Data security is of prime importance, with users only able to access the records of babies that they have permission to see – usually because they are involved in their clinical care.

# What is collected and how is it used?

Data are of limited use unless turned into information that can be used to inform and to improve. The Data Protection Act (1998) states that: "Data shall be obtained only for one or more *specified* purposes and shall not be further processed in any manner incompatible with those purposes". The Act also states that data shall be: "Relevant and not excessive in relation to the purposes for which they are processed". These points are further emphasised in the Caldicott Principles, which apply to the handling of patient-

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identifiable information and are included in the NHS confidentiality code of practice.

The data needed for clinical care will be dictated by the condition and needs of the patient. Use for purposes other than direct clinical care (secondary use of data) has to be considered carefully, keeping in mind the Data Protection Act and the Caldicott Principles. Data used for secondary analysis must be completely anonymous. If patient identifiable data are required, there must be signed informed patient (parent) consent, as for example in research studies, or obtainment of specific permission. Section 60 of the Health and Social Act 2001 (subsequently section 251 of the NHS Act 2006) allows use of patient identifiable information to support essential NHS activity, without the consent of patients but only where, in the interests of patients or the wider public, consent is not a practicable alternative and where anonymous information will not suffice.

It is clear that data must only be collected for specific purposes and should, except in exceptional circumstances, be anonymised. Trusts must have policies in place to ensure that data, particularly patient identifiable data, are not stored or used inappropriately. All users have a duty to adhere to local policies, the Data Protection Act and Caldicott Principles.

## Local use of neonatal data

Units, and their Trusts, use data for a number of purposes including quality assessment, audit, workload monitoring and finance. Data are downloaded to other datasets, eg NCCMDS (for funding in England and Wales), Scottish Birth Record and Neonatal Intensive Care Outcomes Research and Evaluation (NICORE) in Northern Ireland. Standard reports used repeatedly should be part of an electronic system and be easily available to users. There are many possible types of reports; FIGURE 1 gives examples of output that can be created, showing numbers of admissions within a chosen date range broken down by gestation and type. Electronic systems must support unit audit programmes by facilitating easy data downloads, however this requires local resources for the handling and reporting of data.

The commissioning of neonatal services now includes a range of quality measures. The Neonatal Clinical Reference Group will publish standards in addition to other local standards that may exist. Quality



FIGURE 1 An example of a unit report with possible output (BadgerNet).

		Jan 2012	Feb 2012	Mar 2012	Apr 2012	May 2012	Jun 2012	Jul 2012	Aug 2012	Sep 2012	Oct 2012	Nov 2012	Dec 2012	
Adm	inistration													
۲	Total admissions	83	80	91	88	68	87	91	89	83	100	73	0	
۲	Admissions (episode=1)	71	64	70	72	56	71	70	75	73	84	62	0	
Tem	p on admission													Π.
۲	Admissions under 29 weeks gestation (episode=1)	2	4	5	5	3	3	4	4	4	7	6	0	
۲	Temp measured within 1hr of birth	2	3	5	5	3	2	3	3	2	6	4	0	
۲	Temp measured within 1hr of birth (%)	100.0	75.0	100.0	100.0	100.0	66.7	75.0	75.0	50.0	85.7	66.7		I
۲	Temp after admission under 36	0	0	0	0	0	0	0	0	0	0	0	0	
۲	Temp after admission under 36 (%)	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	/////	
Ante	natal steroids													
۲	Gestation between 24 and 34 weeks	12	10	14	7	9	12	12	19	18	14	13	0	
۲	Mothers given antenatal steroids	8	7	10	6	6	11	10	14	13	13	10	0	1
۲	Mothers given antenatal steroids (%)	66.7	70.0	71.4		66.7	91.7		73.7	72.2	92.9	76.9		
Seen	by senior staff													
۲	Admissions seen within 24 hours (episode=1)	65	58	51	35	34	25	42	49	53	58	51	0	
۲	Admissions seen within 24 hours (episode=1) (%)	91.5		72.9	48.6	60.7	35.2	60.0	65.3	72.6	69.0	82.3		
۲	Admissions seen within 24 hours (episode>1)	10	11	14	7	6	7	14	10	7	10	6	0	
۲	Admissions seen within 24 hours (episode>1) (%)	83.3	68.8	66.7	43.8	50.0	43.8	66.7	71.4	70.0	62.5	54.5		
Pare	nteral nutrition													ш
۲	TPN eligible babies	7	7	9	11	5	3	7	11	6	8	0	0	
۲	TPN babies	5	6	9	6	4	2	5	7	6	7	0	0	
۲	TPN babies (%)	71.4		100.0	54.5		66.7	71.4	63.6	100.0		/////	377777	
Brea	stmilk at discharge													
۲	Discharged under 33 weeks	1	2	3	0	0	0	0	0	0	0	0	0	
۲	Breast milk at discharge	1	1	0	0	0	0	0	0	0	0	0	0	
۲	Breast milk at discharge (%)	100.0	50.0	0.0	//////	11111	11111	/////	/////	/////	2/////	/////	11111	-

FIGURE 2 An example of a neonatal unit dashboard (BadgerNet).

standards include measures of process of care (eg the number of babies screened at appropriate time for retinopathy), as well as outcome (eg gestation specific mortality). These should all be evidencebased and shown to improve quality of care and outcome for the newborn baby. Units must monitor how well they are achieving these standards. It is important that the information is fed back quickly so that all staff can be engaged in real-time quality improvement. 'Dashboards' are ideal for displaying data in a way that is easy to understand and with colour coding, show at a glance how well a unit is doing. FIGURE 2 shows an example

dashboard. The levels at which the colours appear can be set by the unit. Clicking on any of the numbers gives a list of the babies that make up the data in that cell.

Increasingly a neonatal service does not work in isolation and data need to be compared across networks and regions (where commissioning may cross several networks), as well as nationally. For purposes of comparison or benchmarking, it is vital that standardised datasets are used so that 'like is compared with like'. Use of a single patient record shared across the N3 network, as with BadgerNet, allows standardisation of data. The content of the dataset is determined



FIGURE 3 An example of a network report with possible output (BadgerNet).

by the reporting requirements. BAPM have previously published a minimum neonatal dataset for annual reports, which is currently under revision.

#### Network and regional use of data

There is a need to monitor the function and outcome of the units making up the network, as well as the networks that make up a region. There are nationally defined standards but networks will also determine their own 'rules' around where and how certain groups of babies are to be managed. The transfer of babies outside the network will need to be monitored. An example of a network report is shown in **FIGURE 3**; network dashboards have also been defined. It is important that units, networks and commissioners work with software providers to ensure data collection is meaningful and useful reports can be developed, with minimal duplication of effort.

With unit data linked across the N3 network it will be possible to monitor patient flows across network boundaries in real-time. 'Exception reporting' is also possible. This gives information in realtime of how units are performing, eg the notification of ventilated babies who have not been transferred to an appropriate unit as determined by the network protocols. There may be many reasons why this occurs, but such reporting allows real-time investigation with potential benefits for the patient.

#### National use of data

The NNAP addresses several questions relating to quality of care and produces an annual report showing unit comparisons. Quality improvement programmes are being developed to investigate and address problems with outliers. As well as clinical outcome measures, this programme attempts to include parent and familyoriented data. NNAP data can be collected as part of routine clinical care.

Many units subscribe to national and international datasets such as the Neonatal Data Analysis Unit (NDAU) in the UK and Vermont Oxford in the USA. These large datasets allow, not only benchmarking, but also more detailed modelling of data looking at various factors that may be responsible for differences in outcome across units and other population groups. They are good at showing population changes over time. Although it may not be possible to prove a hypothesis, the large amount of data can be used to generate hypotheses leading to important areas of future research.

A mechanism for data collection across the UK provides a platform for collection of research data, either from routinely collected data, or from some extra information collected at the time of clinical care (for those units participating in a research project). The data can continue to be collected if a baby moves to another unit, as this is all part of the single patient record.

#### Conclusion

There is an increasing amount of data collected as part of the clinical care of a patient. Everyone involved in health care must keep good clinical notes and has a responsibility to be involved in the use of data to measure quality and efficiency of care. There are responsibilities associated with the secondary use of clinical data that all users must understand and adhere to. Systems must be in place that analyse and report data with rapid and meaningful feedback to clinical teams. There is a need to support the use of information, not only as part of local care, but also at a network and national level. Effective national benchmarking linked to appropriate clinical improvement programmes will help the quality of care and the outcome for the all babies cared for by a neonatal service.

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#### **Conflict of interest**

Andrew Lyon is a retired Consultant Neonatologist who now works with, and receives payment from, Clevermed Ltd.