*Topic Expert Group:* **Data collection and documentation**

# Quality indicators

Webbe J, Lack N, Daly M, Göpel W, Helenius K, Latour J, Modi N, Soll R, Wills-Eve B

## *Target group*

Infants and parents

## *User group*

Healthcare professionals, neonatal units, hospitals, and health services

## *Statement of standard*

Recording, collating and reporting quality indicators in a standardised manner supports comparisons of care nationally, within Europe and beyond.

## *Rationale*

The care provided to neonates affects outcomes in every organ system (1) with implications that extend through childhood (2), into adult life (3), and may affect an individual's offspring. (4) Admission to a neonatal unit also affects parents and the wider family. (5–7) Valid, reliable quality indicators are needed to ensure that the care provided to neonatal patients is evidence-based, of the highest standards, and leads to positive long-term outcomes.

Quality indicators are standardised, evidence-based measures to monitor and evaluate the process, performance or outcomes of neonatal care delivery. (8,9) Recording and reporting these indicators in a standardised manner allows audit, benchmarking, quality improvement, service evaluation and research across Europe: this allows greater understanding of the variation in care provision and outcomes currently seen within (10–12) and between countries. (13,14) The European Standards of Care for Newborn Health (ESCNH) quality indicators identified in this standard include background characteristics required for risk-adjustment (15,16), process measures (17), and neonatal outcomes. (18)

Within Europe, there are a number of regional, national and international databases holding data relating to quality indicators; but coverage is not universal and data are not always comparable between databases. (19) Expanding the coverage of existing databases and creating new databases (where necessary) allows international data combination and comparison. Data should be recorded using standard nomenclatures and internationally recognised terminologies. Ideally, individual data components are captured to allow the application of multiple indicator definitions to ensure meaningful comparisons can be made. For example, by capturing data reporting duration of different modes of ventilation any selected definition of bronchopulmonary dysplasia could be applied across multiple databases. (20) The creation of pan-European databases to improve neonatal care should be compatible with existing international projects (such as the NNRD, eNewborn, iNeo and the Vermont Oxford Network). Comparing quality indicators internationally helps identify optimal practice within Europe, highlights practice deficits, and ensures continued improvement in neonatal outcomes. (21)

## *Benefits*

### *Short-term benefits*

- Improved quality of clinical care of newborns (19,22)

- Facilitated decision-making conversations between parents and healthcare professionals (5,23)

*Long-term benefits*

- Facilitated meaningful comparison of outcomes in populations in different countries within Europe and beyond (24)
- Facilitated meaningful comparisons of outcomes over time (11)
- Better data for quality improvement, audit and research (25)
- Identified priority areas for improvement in services from local to international level (26)

*Components of the standard*

| **Component** | **Grading of evidence** | **Indicator of meeting the standard** |
|---|---|---|
| For parents and family | | |
| 1. Individuals born preterm are informed of the details of their birth and neonatal period so that they can make informed decisions about their ongoing healthcare needs. (27) | A (High quality) | Audit report, parent feedback |
| 2. Former neonatal patients should be able to access their medical records. | B (Moderate quality) | Audit report |
| 3. Clear information about quality indicators is available to parents and former patients in multiple formats (including as written information sheets) (see Data Collection and Documentation). (23,28) | A (High quality) | Audit report, parent feedback, patient information sheet |
| 4. Former neonatal patients and parents are involved in all aspects of projects using quality indicators. (29) | A (High quality) | Parent feedback |
| For healthcare professionals | | |
| 5. All responsible healthcare professionals participate actively in the collection of data relating to quality indicators (as appropriate to their role). | B (Moderate quality) | Guideline |
| 6. Training on quality indicator related data is attended by all responsible healthcare professionals. | B (Moderate quality) | Training documentation |
| For neonatal unit | | |
| 7. Data is collected relating to quality indicators. (18,19,30,31) | A (High quality) | Audit report |
| 8. Data is collected for all neonates (alive and deceased) who receive or have received neonatal care. | B (High quality) | Audit report |

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| For hospital |  |  |
| 9. Data relating to quality indicators are collected, reported, and audited to benchmark local performance and identify areas for improvement. (18,19,30–32) | A (High quality) | Audit report |
| 10. Data relating to quality indicators is contributed to regional and national databases. (18,19,32,33) | A (High quality) | Audit report, regional network |
| For health service |  |  |
| 11. Data relating to quality indicators are collated and reviewed annually. (18,19,32) | A (High quality) | Audit report |
| 12. Data relating to quality indicators are used for benchmarking at national and international level. (18,19,32) | A (High quality) | Policy statement |
| 13. Data relating to quality indicators are made available for research. (19,31) | A (High quality) | Guideline |
| 14. Data relating to quality indicators are available for policy-makers to guide priority setting. | B (High quality) | Policy statement |

*Where to go – further development of care*

| **Further development** | **Grading of evidence** |
|---|---|
| For parents and family |  |
| • The views of parents and former neonatal patients are included in data collection and analysis. (19,23) | A (High quality) |
| • Information sheets to inform parents and former patients about quality indicators are co-designed. (23) | A (High quality) |
| • A written, infant-focused lay summary detailing the care a patient has received is given to all families when their infant is discharged home. | B (Moderate quality) |
| For healthcare professionals |  |
| • Ensure data entry for all variables is completed to high standards. (33–36) | A (High quality) |
| For neonatal unit |  |
| • Ensure data entry for all variables is completed to high standards. (33–36) | A (High quality) |
| • Evaluate the involvement of former neonatal patients and parents in projects related to quality indicators annually. (29) | A (High quality) |
| For hospital |  |
| • Collect data for all live born neonates. | B (High quality) |
| • Extract data, whenever possible, automatically from electronic records to minimise the burden on clinical staff. | B (Moderate quality) |

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| • Contribute data relating to quality indicators to regional and national databases. (18,30) | A (Moderate quality) |
| For health service | |
| • Ensure that data relating to quality indicators covers the entire population. | B (High quality) |
| • Collate and review data relating to quality indicators annually. (18,30) | A (Moderate quality) |
| • Establish a regular, pan-European audit of the European Standards of Care for Newborn Health. | B (High quality) |
| • Compare quality indicators internationally and over time to identify areas to prioritise. (11,13,31) | A (High quality) |
| • Compare outcomes beyond Europe (e.g. with NNRD, iNeo, eNewborn and VON) to ensure European neonatal care is among the best globally. (13,19,32,33) | A (High quality) |

## *Getting started*

**Initial steps**

For parents and family

- Information about quality indicators should be available to parents and former patients orally.

For healthcare professionals

- Participate in the collection of data relating to quality indicators.

For neonatal unit

- Collect data relating to quality indicators for all neonates admitted to the neonatal unit.
- Create local systems to allow data collection and recording.

For hospital

- Collect, report and audit data relating to quality indicators in order to benchmark local performance and identify areas for improvement.

For health service

- Collate data relating to quality indicators at regional and national level.

## *Description*

### *Quality indicators*

The European Standards of Care for Newborn Health (ESCNH) quality indicators are variables required for collection and reporting of standardised data. They include background variables required for extensive risk-adjustment, process measures and important neonatal outcomes. The variables have been derived from: a systematic review of existing databases (19), a systematic review of the background characteristics reported in clinical trials (15), international consensus projects (18,30), and the variables included in validated prognostic models. (16)

These indicators should be recorded and reported using standard nomenclature, in line with internationally recognised terminology. However, we acknowledge that for most quality indicators no global consensus exists as to the ‘perfect’ definition or measurement tool (37–39): instead, we propose that capturing individual data components using recognised, validated definitions will provide the flexibility needed to apply different definitions to the data and facilitate meaningful comparisons between databases. It is also essential that suitable denominator data are available to allow meaningful comparison between populations:  for this to occur demographic data relating to all live births, defined according to the AAP definition (40), should be available.

Timing of assessment and data collection is important: as a minimum, it should be in line with standardised assessments, but collecting and recording more frequent data will facilitate the application of multiple definitions. Furthermore, some of the indicators include long-term outcomes. The impact of preterm birth has been clearly shown to extend throughout childhood and into adult life and so, outcomes should be collected into adulthood. To achieve this, collaboration will be needed to ensure that data can be linked between different databases. This work is now possible because data capture and storage technologies are improving and international collaborations are expanding allowing maximal use of available data. Future work to establish a European database will create a tiered structure of responsibility at regional, national and pan-national levels.

| Indicator | Suggested data components |
|---|---|
| **Background characteristics** | |
| Maternal factors | |
| Antenatal care | 1. Whether the mother accessed antenatal care<br>(see Birth & transfer) |
| Antenatal steroid exposure | 2. Type of steroids<br>3. Date and time of doses |
| Barriers to care | 4. Whether any barriers exist preventing patients from accessing antenatal or neonatal care (e.g. cultural, financial) |
| Maternal age | 5. Maternal age in years at birth |
| Maternal complications of pregnancy | 6. Reported using standardised terminology according to an accepted definition |
| Maternal drug use | 7. Drug use status at first antenatal contact (including prescribed medications and illicit substances)<br>8. Use of drugs during pregnancy |
| Maternal education | 9. Reported using standardised terminology according to an accepted definition |
| Maternal ethnicity | 10. Reported using standardised terminology according to an accepted definition |
| Maternal medical problems | 11. Reported using an accepted definition |
| Maternal smoking status | 12. Smoking status at first antenatal contact<br>13. Number of cigarettes smoked during pregnancy |
| Maternal socio-economic status | 14. Reported using standardised terminology according to an accepted definition |

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| Labour and delivery | |
| Duration of rupture of membranes | 15. The time from rupture of membranes to birth |
| Highest maternal temperature during labour | 16. The highest recorded maternal temperature during labour |
| Location of delivery: maternity | 17. The level of maternity care provided at the location of delivery |
| Location of care: neonatal | 18. The level of neonatal care provided at the location of delivery<br>(see Birth & transfer) |
| Mode of delivery | 19. Reported using standardised terminology according to an accepted definition |
| Presentation of foetus at delivery | 20. Presentation prior to delivery |
| Infant factors | |
| 1 minute Apgar score | 21. Apgar score one minute after birth |
| Birth weight | 22. Birth weight at the time of delivery in grams |
| Congenital anomaly | 23. Reported using standardised terminology according to an accepted definition |
| Gestational age | 24. Gestational age at birth of neonate in whole weeks and remaining days |
| Plurality | 25. Number of foetuses during pregnancy |
| Sex | 26. Phenotypic sex of neonate |
| **Process measures** | |
| Delayed cord clamping | 27. Duration from live birth to cord clamping |
| Family-centred care | 28. Reported using standardised terminology according to an accepted definition<br>(see Infant- & family-centred developmental care) |
| Feeding during admission | 29. Timing of feeding<br>30. Route of feeding<br>31. Choice of milk<br>32. Volume of milk<br>(see Nutrition) |
| Long-term follow up | 33. Whether a neonate received appropriate long-term follow up<br>(see Follow-up & continuing care) |
| Minimising inappropriate separation | 34. Whether a neonate was separated from their mother without clinical indication<br>(see Infant- & family-centred developmental care) |
| Nurse staffing ratios | 35. Whether the neonate received a suitable level of nursing care throughout their stay<br>(see Patient safety & hygiene practice) |

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| Parenteral nutrition | 36. Whether the neonate received parenteral nutrition<br>37. Formulation of parenteral nutrition<br>38. Route of parenteral nutrition<br>39. Duration of parenteral nutrition<br>(see Nutrition) |
| Screening for retinopathy of prematurity | 40. Whether the neonate underwent screening for retinopathy of prematurity (if indicated)<br>41. Timing of screening for retinopathy of prematurity<br>(see Medical care & clinical practice) |
| Surfactant administration | 42. Doses of surfactant received<br>43. Formulation of surfactant<br>44. Route of surfactant |
| **Outcomes** | |
| Adverse events | 1. Any harm from care during the neonatal period reported using standardised terminology according to an accepted definition |
| Brain injury (on imaging) | 2. Timing of scans<br>3. Pathology seen on scan, reported using standardised terminology according to an accepted definition |
| Chronic lung disease/bronchopulmonary dysplasia | 4. Mode of respiratory support<br>5. Duration of respiratory support |
| General cognitive ability | 6. Timing of milestones<br>7. Timing and results of testing, reported using standardised terminology according to an accepted definition |
| General gross motor ability | 8. Timing of milestones<br>9. Timing and results of testing, reported using standardised terminology according to an accepted definition |
| Hearing impairment or deafness | 10. Timing of hearing tests<br>11. Results of hearing tests |
| Necrotising enterocolitis | 12. Timing and results of relevant biochemical and radiological testing<br>13. Clinical features<br>14. Timing and findings at surgery |
| Pain | 15. Reported using standardised terminology according to an accepted definition |
| Pulmonary function | 16. Reported using standardised terminology according to an accepted definition |
| Quality of life | 17. Reported using standardised terminology according to an accepted definition |

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|---|---|
| Retinopathy of prematurity | 18. Timing and results of screening<br>19. Timing and mode of therapy |
| Sepsis | 20. Timing and results of relevant biochemical and microbiological testing<br>21. Clinical features |
| Social functioning | 22. Reported using standardised terminology according to an accepted definition |
| Survival | 23. Timing of death<br>24. Survival to discharge home |
| Visual impairment or blindness | 25. Timing of vision tests<br>26. Results of vision tests |

## *Source*

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