



Topic Expert Group: Data collection and documentation

Accessibility of information

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Target group

Infants and parents

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard

Information on the quality of neonatal healthcare is collected, accessible, and understandable at national, regional, and hospital level.

Rationale

Information on the quality of neonatal healthcare is required for understanding and improving health outcomes. (1) This implies that well-constructed, comparable performance indicators based on timely, high-quality, risk-adjusted data are easily accessible to parents, healthcare professionals, and decision makers (1,2) (see TEG Data collection and documentation) Information portals should reflect national and international benchmark programmes (1,3) as analysis of comparable data at national level can highlight differences in healthcare between countries. (3,4) This provides diverse stakeholders with important information on structural, procedural, or outcome-related regional (5) differences in healthcare and on the allocation of resources. (6)

However, systematic structured data collection is often neither organised at obstetrical or neonatal units nor coordinated nationally. Available information is not standardised, accessible, or understandable by parents and healthcare professionals. Regular, interactively scalable reports are lacking.

Effective reporting would reach all target groups, provide answers to a broad range of questions, and help to develop prevention strategies. By applying methods for inter-hospital and regional comparisons, easy readability, differentiated interpretation, and analysis of trends over time is facilitated. Participation of units in national and international surveillance and research networks leads to collective work improving data quality and performance indicators. In reporting, principles for providing evidence-based information and data for patients should be followed. (7,8)

Benefits

- Increased attention to the variation in quality of care (consensus)
- Easier identification of areas of good practice (consensus)
- More objective view on healthcare data (consensus)
- Easier access to data (consensus)
- More attractive and thus more widely read reports (consensus)
- Improved quality of published data (consensus)
- Better informed parents and families (consensus)



- Harmonised data, classifications and definitions on an international level (consensus)
- Improved overall data quality (consensus)
- Improved quality of care through benchmarking process (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and families		
1. Parents are informed of data collection and the purposes to which it will be used by healthcare professionals.	B (High quality)	Parent feedback, parent information sheet
2. Data presentation is easily and intuitively understandable also for parents. (7–9)	B (Moderate quality)	Parent feedback
For healthcare professionals		
3. A consented guideline on data entry is adhered to by all healthcare professionals.	B (High quality)	Guideline
4. Training on data entry and on the importance and rationale of data collection is attended by all responsible healthcare professionals.	B (High quality)	Training documentation
For neonatal unit		
5. A consented guideline on data entry and the use of (inter-)nationally agreed datasets is available and regularly updated.	B (High quality)	Guideline
6. Data collected for surveillance are employed to evaluate healthcare practices and the organisation of healthcare practices and the organisation of healthcare for patients and families.	B (Moderate quality)	Audit report
7. Participation within local, national, and international surveillance and research networks is aimed for in order to develop methods for comparison across units.	B (Moderate quality)	Audit report
For hospital		
8. Training on data entry is ensured.	B (High quality)	Training documentation



9. Regular reports for analysis of temporal changes and local outcomes are available. (1,2,10,11)	A (Moderate quality)	Audit report
10. A system for quality assurance for the data collection process is established.	B (Moderate quality)	Audit report, guideline
11. Reports are systematically analysed and risk related interventions are initiated.	B (Moderate quality)	Audit report, guideline
12. Quality reports are publicly available.	B (Moderate quality)	Audit report, parent feedback

For health service

13. A national guideline on infrastructure for data capture and analysis, data entry, and the use of (inter-)nationally agreed datasets is available and regularly updated.	B (High quality)	Guideline
14. Comparative data is used to benchmark outcomes (e.g. mortality and morbidity) at hospital, regional, national or international level over time adjusted for patient characteristics.	B (Moderate quality)	Audit report
15. Researchers, clinicians, policy-makers, parents, and users are involved in benchmarking processes in order to guarantee high quality and clinical and societal relevance.	B (Moderate quality)	Audit report
16. National neonatal outcomes are collated to inform policy decisions.	B (Low quality)	Audit report
17. Data is used for research and surveillance by trained epidemiologists and statisticians.	B (High quality)	Audit report

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
<ul style="list-style-type: none">Parents are given an active role in developing information policy.	B (Moderate quality)



For health care professionals

- Coordinate with research networks to analyse data for (scientific) publications. B (Moderate quality)

For neonatal unit

N/A

For hospital

- Use automated record systems. B (Moderate quality)
- Follow high standards in reporting and accessibility of data. (10,11) A (High quality)

For health service

- Formalise international collaboration between stakeholders. B (High quality)
- Develop data comparison on an international level. (5) A (Moderate quality)

Getting started

Initial steps

For parents and family

- Parents are verbally informed of data collection and the purposes to which it will be used by healthcare professionals.
- Parents' concerns are integrated into the health information systems.

For healthcare professionals

- Attend training in data entry and about the importance and rationale of data collection.
- Collaborate with national professional healthcare societies.

For neonatal unit

- Implement a consented guideline on data entry and the use of (inter-)nationally agreed datasets.
- Develop information material on data collection and the purposes to which it will be used for parents.
- Identify a person/team responsible for data quality.

For hospital

- Support healthcare professionals to participate in training in data entry and about the importance and rationale of data collection.

For health service

- Develop and implement a national guideline on infrastructure for data capture and analysis, data entry and the use of (inter-)nationally agreed datasets.
- Provide infrastructure for data capture and analysis.
- Define respective minimum datasets and provide suitable technology for their recording and analysis.

Source

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Lifecycle

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