



# Data collection & documentation



*Topic Expert Group*

**Data collection and documentation**

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

### Overview

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, and risk-adjusted data are standardised and easily accessible as well as understandable for parents, healthcare professionals, and decision makers. (1,2) At the moment, systematically structured data collection is often neither organised at obstetric or neonatal units nor coordinated on a national or even on an international level. Regular, interactively scalable reports are lacking. Furthermore, quality and health indicators which best reflect the needs and are the most relevant to document quality of neonatal care, are not yet identified. (3–6)

Effective reporting would reach all target groups, provide answers to a broad range of questions, and help to develop prevention strategies. Long-term follow-up is essential for evaluating outcomes, especially for high-risk newborn infants. (7) By applying methods for inter-hospital, regional, national, and international comparisons, easy readability, differentiated interpretation, and analysis of trends over time is facilitated. Information portals should reflect these national and international benchmark programmes (1,8) comparing data at national level to highlight differences in healthcare between countries. (8,9) These data provide diverse stakeholders with important information on structural, procedural, or outcome-related regional (10) differences in healthcare and on the allocation of resources. (11) In reporting, principles for providing evidence-based information and data for patients should be followed. (12,13)

The Topic Expert Group on Data collection and documentation develops standards related to the acquisition and use of perinatal and neonatal data.

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## **Accessibility of information**

Lack N, Bréart G, Bloch VVH, Gissler M, Göpel W, Haumont D, Hummler H, Loureiro B, Vavouraki E, Zeitlin J

### *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*

<b>Component</b>	<b>Grading of evidence</b>	<b>Indicator of meeting the standard</b>
<b>For parents and families</b>		
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
<b>For healthcare professionals</b>		
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
<b>For neonatal unit</b>		
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
<b>For hospital</b>		
8. Training on data entry is ensured.	B (High quality)	Training documentation Audit report
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
<b>For health service</b>		
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*

<b>Further development</b>	<b>Grading of evidence</b>
<b>For parents and family</b>	
<ul style="list-style-type: none"> <li>Parents are given an active role in developing information policy.</li> </ul>	B (Moderate quality)
<b>For health care professionals</b>	
<ul style="list-style-type: none"> <li>Coordinate with research networks to analyse data for (scientific) publications.</li> </ul>	B (Moderate quality)
<b>For neonatal unit</b>	
N/A	



#### For hospital

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

#### 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*

10 years/next revision: 2028

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## Characteristics of health indicators

Lack N, Bréart G, Bloch VVH, Gissler M, Göpel W, Haumont D, Hummler H, Loureiro B, Vavouraki E, Zeitlin J

### *Target group*

Infants and parents

### *User group*

Healthcare professionals, neonatal units, hospitals, and health services

### *Statement of standard*

Quality and health indicators in neonatal healthcare comply with published standards and help to increase comparability.

### *Rationale*

Quality and health indicators help to measure and compare quality of care and health services with the purpose of monitoring progress towards defined goals. They are essential for informing policy, managing the healthcare system, enhancing our understanding of the broader determinants of health, as well as identifying gaps in health status and outcomes of specific populations. Furthermore, indicators provide concise information of health situation and trends. While there are countless indicators that could be used, the challenge is to identify those which best reflect the needs and those which are the most relevant to document quality of neonatal care. (1–4) Especially for high-risk newborn infants long-term follow-up is essential for evaluating outcomes (5) and this longitudinal perspective must be considered when identifying indicators to assess standards of care.

Countries can use indicators for monitoring in accordance with their own health priorities and capacity, as they allow comparisons between quality of care and health services and assessment of the impact of particular factors on the quality of national health services. (6)

Indicators are based on standards of care. The demand for valid and reliable data to ensure informed decision making implies that indicators are constructed according to standard methods. To ensure that reliable and valid indicators are used, they must be designed, defined, and implemented rigorously. Availability and quality of indicators can be improved by combining existing data sources from vital statistics, hospital data, and other registers. (7,8) A comprehensive list of accepted standard methods exists and may be drawn upon. (9–14)

### *Benefits*

- Consistent reporting in health outcomes and quality of care (consensus)
- Increased comparability of quality of healthcare over time and different locations (consensus)
- Easily understandable indicators of healthcare (consensus)
- Facilitated judgements and setting of priorities (consensus)
- Facilitated measurement and tracking clinical performance and outcomes (consensus)
- Monitoring and evaluation of healthcare quality (consensus)



- Improved quality of healthcare (consensus)
- Increased availability of trend analyses (consensus)
- Facilitated collaboration across sectors (consensus)
- Facilitated benchmark reporting (consensus)
- Worldwide comparability of healthcare indicators (consensus)

### *Components of the standard*

<b>Component</b>	<b>Grading of evidence</b>	<b>Indicator of meeting the standard</b>
<b>For parents and family</b>		
1. Parents are informed about collection of personal data where not automatically protected by local legislation.	B (High quality)	Audit report, parent feedback
2. Patient reported outcome measures are considered and carefully defined in the development of healthcare indicators. (15)	A (Low quality)	Audit report, parent feedback
3. Parents are involved in the development of healthcare indicators. (10,11,16)	A (Low quality)	Parent feedback
<b>For healthcare professionals</b>		
4. Information on the importance and appropriateness of healthcare indicators is included within the curricula.	B (Low quality)	Training documentation
<b>For neonatal unit and hospital</b>		
5. Healthcare indicators are used for reporting.	B (Moderate quality)	Audit report
<b>For health service</b>		
6. A national policy statement on the use of valid and reliable healthcare indicators for reporting is available and regularly updated.	B (High quality)	Policy statement
7. Healthcare indicators need to be selected according to determined and common criteria. (1,8,10,14)	A (Moderate quality)	Audit report
8. Standardised reporting at national and international level is carried out (12,13) and results in appropriate action. (9,10)	A (Moderate quality) B (Moderate quality)	Audit report



9. Routine data is available for research to ensure development of better indicators and the analysis of data for improving practice and policy.	B (Moderate quality)	Clinical records, guideline
10. In recordings of births and deaths, international recommendations are adhered to. (17)	B (Moderate quality)	Guideline

*Where to go – further development of care*

Further development	Grading of evidence
For parents and family	
N/A	
For healthcare professionals	
N/A	
For neonatal unit and hospital	
N/A	
For health service	
<ul style="list-style-type: none"> <li>• Harmonise international healthcare indicators.</li> <li>• Develop novel healthcare indicators, e.g. quality of life, parent satisfaction, family-centred care, and well-being.</li> <li>• Contribute to higher quality global databases of health results.</li> </ul>	<p>B (High quality)</p> <p>B (High quality)</p> <p>B (High quality)</p>

*Getting started*

Initial steps
For parents and family
<ul style="list-style-type: none"> <li>• Define areas of interest for which data are needed.</li> </ul>
For healthcare professionals
<ul style="list-style-type: none"> <li>• Define areas of interest for which data are needed.</li> </ul>
For neonatal unit and hospital
<ul style="list-style-type: none"> <li>• Analyse patient outcome and define a minimum dataset for indicators of quality measures.</li> </ul>
For health service
<ul style="list-style-type: none"> <li>• Implement information of the importance of healthcare indicators in the curriculum.</li> <li>• Develop and implement a policy statement on the use of valid and reliable healthcare indicators for reporting.</li> <li>• Identify and define a core set of indicators and measurement needs for women’s and infants’ health.</li> </ul>



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