



Data collection & documentation

Accessibility of information

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Statement of the standard

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



For parents and family

- Parents are informed of data collection and the purposes to which it will be used by healthcare professionals. Parents are equally recommended (also through parents' associations) to ask units, hospitals, health services to report their data clearly.
- Data presentation is easily and intuitively understandable also for parents.



For neonatal unit

- A consented guideline on data entry and the use of (inter-)nationally agreed datasets is available and regularly updated.
- 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.
- Participation within local, national, and international surveillance and research networks is aimed for in order to develop methods for comparison across units.



For healthcare professionals

- A consented guideline on data entry is adhered to by all healthcare professionals.
- Training on data entry and on the importance and rationale of data collection is attended by all responsible healthcare professionals.

Benefits

- Increased attention to the variation in quality of care
- Easier identification of areas of good practice
- More objective view on healthcare data
- Easier access to data
- More attractive and thus more widely read reports
- Improved quality of published data
- Better informed parents and families
- Harmonised data, classifications and definitions on an international level
- Improved overall data quality
- Improved quality of care through benchmarking process



For hospitals

- Training on data entry is ensured.
- Regular reports for analysis of temporal changes and local outcomes are available.
- A system for quality assurance for the data collection process is established.
- Reports are systematically analysed and risk related interventions are initiated.
- Quality reports are publicly available.



For health service

- 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.
- Comparative data are used to benchmark outcomes at hospital, regional, national or international level over time adjusted for patient characteristics.
- Researchers, clinicians, policy-makers, parents, and users are involved in benchmarking processes in order to guarantee high quality and clinical and societal relevance.
- National neonatal outcomes are collated to inform policy decisions.
- Data is used for research and surveillance by trained epidemiologists and statisticians.

