

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.
- 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 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.

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 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.



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 is used to **benchmark** outcomes (e.g. mortality and morbidity) 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.

