European Standards of Care for Newborn Health project

Dr. Johanna Walz, Head of Scientific Affairs, EFCNI
EFCNI – a strong network for maternal and newborn health

• First pan-European organisation to represent the interests of preterm and ill newborn infants and their families
• Combine forces of parents, healthcare experts, scientists → reducing preterm birth rates and improving outcomes

• Fields of activities
  • Preconception and maternal care
  • Treatment and care
  • Continuing care

A strong partnership with…

- >100 national parent / patient organisations worldwide
- >20 global healthcare societies
- >30 European healthcare societies
- >80 national healthcare societies

- Supranational organisations (WHO, …)
- European institutions (EU parliament, commission, EMA,…)
- G7 preparation-meetings
European Standards of Care for Newborn Health (ESCNH) project

1. Background – Why are standards needed?
2. The project – Why is it so unique?
3. The process – How were the standards developed?
4. Overview – The topics of the standards
5. Where to find the standards
6. Call to Action
7. What has been achieved so far?
8. Outlook
Differences between European countries

- Infrastructure for high-risk pregnancies
- Organisation of medical centres
- Transport systems
- Education of healthcare professionals
- Follow-up and continuing care
- Medical treatment
- Level of implementation of infant- and family-centred care
- Nutrition
- NICU design
Wide differences in maternal and newborn health in Europe

Policies towards family visiting in NICU:s
Still several barriers, particularly in the South European countries

n = 9 9 35 10 10 45 22 35

- Allowed for both parents over 24 h
- Allowed for both parents over 24 h and visit duration unlimited
- Allowed for both parents over 24 h, visit duration unlimited and no other restrictions*
- Allowed for both parents over 24 h, visit duration unlimited, no other restrictions* and visits allowed during medical rounds

G Greisen m.fl 2009
Wide differences in maternal and newborn health in Europe – 24 hours access
Wide differences in maternal and newborn health in Europe

- Wide differences among European countries in maternal and newborn health
  - Neonatal mortality rates range from 0.7 to 4.4 per 1000 live births
  - Infant mortality rates range from 1.5 to 7.6 per 1000 live births
  - Preterm birth percentages range from 5.4% – 12.0% of live births

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Why is this project so unique?

- Initiated by patient (parent) representatives for patients
- Parents are involved in every step of the development process → A true patient centred project
- About 220 experts from more than 30 countries developed the standards
- Supported by more than 150 professional healthcare societies and parent/patient organisations
- Covers the complexity of neonatal care
- Promotes the equitable and high levels of care
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Milestones in improving maternal and newborn health

2008
Declaration of Rome

Catalogue of 10 demands for preterm infants

2010
EU Benchmarking Report

2011 / 2012
European White Paper & Call to Action

Situation in Europe

Key finding:
Different practices, lack of standards

Need for change

Standards to increase quality of care

Establishment of reference

Background, challenges, recommendations

2010 EU Benchmarking Report

Key finding:
Different practices, lack of standards

Situation in Europe
Project start in the European Parliament

- Official start on 7 April 2014 in EU Parliament in Brussels
- Support by many professional organisations and parent organisations
- Symbolic signing of roll-up by all present stakeholders
European Standards of Care for Newborn Health Project

Aim
Development of reference standards for a broad area of topics in newborn health
Development process of the standards

Decision on standard topics by Chair Committee

36 members

Development of template for the standards by Chair Committee

Approval by chairs

First standard draft written by one or more responsible authors as members of the TEG

220 authors

Peer review process:
- Feedback from TEG members and EFCNI
- In case additional user perspective is needed: involvement of the Parents’ Knowledge Forum and external experts

Review by the authors

Final formatting

Voting on the standards by the Chair Committee; 80% yes votes needed

80%

Chairs voted on every single standard separately

Revision of the standards after a certain life cycle and extension of the standard topics

Now it's time to act!

Launch of the standards and the Call to Action in Brussels and publication on: https://newborn-health-standards.org

Support of the standards by healthcare societies, parent/patient organisations, and related Third Parties

Support by >150 organisations

Life Cycle

Implementation
Standard template – the structure of a standard

Components of the standard

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are verbally informed by healthcare professionals</td>
<td>B (high quality)</td>
<td>Relevant information sheet</td>
</tr>
<tr>
<td>2. Parental education on infant nutrition</td>
<td>C (low quality)</td>
<td>Standard</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. A guideline on infant nutrition</td>
<td>A (high quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>2. A unit guideline on infant nutrition</td>
<td>B (high quality)</td>
<td>Guideline</td>
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<tr>
<td>3. A protocol for infant nutrition</td>
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<td>For neonatal unit</td>
<td></td>
<td></td>
</tr>
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<td>Standard</td>
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<tr>
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<td>Guideline</td>
</tr>
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<td>2. Develop and implement a guideline on infant nutrition, including use of parenteral nutrition</td>
<td>C (low quality)</td>
<td>Standard</td>
</tr>
<tr>
<td>For health service</td>
<td></td>
<td></td>
</tr>
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Where to go – further development of care

<table>
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<th>Further development</th>
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Additional information can be given in the "Description" section of the template

The "Source" section shows the scientific evidence behind the standard

All standards are first launched in November 2018. In case of revisions, the number of edition will increase, and the new release date will be displayed here

The standard will be considered for review latest at this time point. The lifecycle of each standard can be three, five, or ten years

The recommended citation of each standard
Grading of evidence system

A: Evidence from research
B: Evidence based on cultural values
C: Evidence from laws, regulations

• Needed for implementation
• Needed for components for which there is no scientific evidence
• In cases where A grading is not possible, B and C might be helpful to strengthen the standards
• B and C grading can be used optionally
• At least one grading for each component
## A. Evidence from research

<table>
<thead>
<tr>
<th>Quality</th>
<th>Further research impact on confidence in estimate of effect</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High quality</strong></td>
<td>Further research is very unlikely to change our confidence in the estimate of effect</td>
</tr>
<tr>
<td><strong>Moderate quality</strong></td>
<td>Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate</td>
</tr>
<tr>
<td><strong>Low quality</strong></td>
<td>Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate</td>
</tr>
<tr>
<td><strong>Very low quality</strong></td>
<td>Any estimate of effect is very uncertain</td>
</tr>
</tbody>
</table>
B: Evidence based on cultural values as judged by project’s experts during the development of the standards in 2018

<table>
<thead>
<tr>
<th>Quality Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>High quality</td>
<td>Based on cultural values that are shared within the geographical Europe</td>
</tr>
<tr>
<td>Moderate quality</td>
<td>Based on cultural values that are shared on a national level, in one or more countries within Europe</td>
</tr>
<tr>
<td>Low quality</td>
<td>Based on cultural values that are shared on a local level within a country within Europe</td>
</tr>
<tr>
<td>Very low quality</td>
<td>Based on cultural values that are subjective at the hospital or individual level</td>
</tr>
</tbody>
</table>
C: Evidence from laws, regulations, or court practice

<table>
<thead>
<tr>
<th>C. Evidence (legal certainty) from laws, regulations, or court practice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High quality</strong> — Required by EU wide valid laws, regulations and other legal sources</td>
</tr>
<tr>
<td><strong>Moderate quality</strong> — Required by national laws, regulations and other legal sources</td>
</tr>
</tbody>
</table>
### Components of the standard

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<tr>
<th>Component</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>For parents and family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are informed by healthcare professionals about the life limiting conditions of their infant and family support options.</td>
<td>B (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>2. Infants with life limiting conditions receive appropriate medication and care. (1,2,11,12)</td>
<td>A (Moderate quality) B (Moderate quality) C (Moderate quality)</td>
<td>Clinical records</td>
</tr>
<tr>
<td>3. Parents are supported in a way that meets their needs and respect their wishes. (1,3,4,10,8,13) (see TEC Infant- and family-centred developmental care)</td>
<td>A (Moderate quality) B (Moderate quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>4. Parents are supported in their grief rituals. (14,15)</td>
<td>A (Low quality) B (Moderate quality)</td>
<td>Parent feedback</td>
</tr>
</tbody>
</table>
Grading of evidence – examples

Long-term benefits

- Reduced mortality and improved neurodevelopmental outcome (2,11)

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<tr>
<td>1. Parents and family are informed by healthcare professionals about</td>
<td>A (Moderate quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>practices to reduce the incidence of nosocomial infections. (9,10)</td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. A unit guideline on screening for multi-resistant bacteria and</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>regarding measures that need to be taken in the event of a positive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>screening is adhered to by all healthcare professionals.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Training on infection prevention practices are attended by all</td>
<td>A (High quality)</td>
<td>Training documentation</td>
</tr>
<tr>
<td>responsible healthcare professionals. (2,9,10)</td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>4. Frequent contact with dedicated infection control teams to discuss</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>specific cases is ensured.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Categories

- Patient safety & hygiene practices

Archives

- Patient safety & hygiene practices
Indicator of meeting the standard

- Indicators for each standard component

→ for later benchmarking/measurement and verification activities whether a component is met after the implementation of the standard

**Examples:**
- Patient information sheet
- Training documentation
- Audit report
- Guideline
- Training documentation
- Clinical records
Project video

https://www.youtube.com/watch?v=vXVY7uVcn3w
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Neonatal care – divided into 11 area = 11 Topic Expert Groups (TEGs)

Topics in the European Standards of Care for Newborn Health project

Birth & transfer
Medical care & clinical practice
Care procedures
Infant- & family-centred developmental care
NICU design
Nutrition
Ethical decisions
Follow-up & continuing care
Patient safety & hygiene practice
Data collection & documentation
Education & training
# TEG Infant- & family-centred developmental care

## Statements of the standards

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A managed acoustic environment</strong> reduces stress and discomfort for infants.</td>
<td><strong>Parents</strong> are members of the caregiving team and, with individualised support, assume the primary role in the provision of care of their infant, and are active partners in decision-making processes.</td>
</tr>
<tr>
<td>An individual <strong>case management plan for each newborn infant</strong> is established, in collaboration with parents, to plan and coordinate needed investigations and procedures, ensure the acquisition of needed parental competences prior to discharge and to plan follow-up and continuing care.</td>
<td><strong>Parents</strong> (and substitutes designated by the parents) have continuous access and are able to remain with the infant throughout the 24 hours.</td>
</tr>
<tr>
<td><strong>Skin-to-skin contact</strong> between mother or father and newborn infant is initiated as early as possible and maintained continuously.</td>
<td><strong>The fostering of early bonding between parents and their newborn infant</strong> is pursued through strategies which promote early contact for the parent-infant dyad.</td>
</tr>
<tr>
<td><strong>The family receives care in an environment where their socioeconomic, mental health and spiritual needs are supported.</strong></td>
<td><strong>Healthcare professionals</strong> receive counselling and regular clinical supervision in communicating with and providing emotional support for parents.</td>
</tr>
<tr>
<td><strong>The hospital sensory environment is adjusted to the infants’ sensory expectancies and perceptual competences.</strong></td>
<td><strong>Managed acoustic environment</strong></td>
</tr>
</tbody>
</table>

- Parents as primary caregiver
- Continuous access throughout the 24 hours
- Fostering early bonding through early contact
- Skin-to-skin contact
- Case management plan for each newborn infant
- Parents receive care taking socioeconomic, mental health and spiritual needs into account
- HCPs receive counselling in communicating with parents
- Training on infant- and family-centred developmental care is ensured
Parents are mobilized into the team and, with individual case management, assume the primary role of providing care of their infant, enabling participation in decision-making.

An individual case management plan for each newborn infant is drafted in collaboration with the parents, in line with their socio-economic, mental health and spiritual needs. The plan ensures parental competencies and to plan follow-up appropriately.

When a traumatic event such as the preterm birth of a child happens, the family should feel welcome, be supported and involved in the care of the newborn baby.

Parents must be allowed to stay close to their baby to establish an early emotional and also helpful bond, and to become autonomous at the time of their child's discharge.

Monica Ceccatelli, Vivere Onlus, Italy

- Managed acoustic environment
- Sensory environment
TEG Care procedures

**Statements of the standards**

The process of taking blood samples is carried out using optimal comfort strategies to minimise stress and pain using an individualised supportive technique.

Appropriate mouth care is given to infants according to their individual needs and to minimise aversive responses.

*Taking blood samples*

Mouth care

Nappy change

Positioning support

Feeding tubes

Support of breastfeeding

Skin protection

Weighing

Activities of daily living

Management of temperature and humidity

Respect of sleep

Comfort to minimise stress and pain

Involvement of parents as much as possible

→ Involvement of parents as much as possible
TEG NICU design

**Statements of the standards**

- Facilitation of parental presence and optimal working environment
- Facilitation of closeness and skin-to-skin care
- Promotion of the family as primary care giver

A NICU is designed to support safety and healing through unrestricted parental presence, use of sensory supportive material and optimal working facilities, promoting close collaboration between families and staff in caring for the ill infant.

Neonatal care is optimised by utilising key design elements to promote the family as primary care givers throughout the stay.

A physical environment that facilitates parent-infant closeness and skin-to-skin care is considered in NICU planning.
TEG Nutrition

Statements of the standards

- Guidelines on nutritional care
- Parenteral nutrition
- Preterm formula
- Early enteral feeding
- Growth monitoring and assessment
- Parental knowledge about feeding
- Early nutrition with human milk
- Supplements
- Donor milk
- Breast feeding
TEG Ethical decision making & palliative care

Statements of the standards

Parents and healthcare professionals share all relevant information such as the conditions, prognosis, and choices for care of the infant, as well as the social situation, values, and preferences of parents.

The rights of infants, parents, and families in difficult decisions are respected by healthcare professionals. The values behind any decisions that may compromise those rights are transparent.

Decisions of withholding or withdrawing life support are based on shared decision-making between parents and healthcare team taking into account the best interest of the infant and family in the context of the clinical situation and legal frameworks.

Interdisciplinary neonatal palliative care safeguards the quality of life of the infant and the family when a life limiting condition is diagnosed.

- All relevant information are shared
- Rights of infants, parents and families are respected
- Shared decision-making on withholding or withdrawing life support
- Interdisciplinary neonatal palliative care is applied
# TEG Follow-up & continuing care

**Statements of the standards**

<table>
<thead>
<tr>
<th>Standardised assessment of neurological status and motor development is conducted in the first two years and repeated at transition to school.</th>
<th>Behaviour, emotional and attention problems are assessed at two years of age and again at the time of transition to school.</th>
<th>Families receive a comprehensive discharge management plan to facilitate transition from the hospital to home.</th>
<th>Standardised assessment of communication, speech, and language development is conducted by two years of age and repeated at transition to school.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer and sibling relationships are evaluated as part of a standard follow-up programme.</td>
<td>Respiratory health is evaluated as part of a follow-up care programme.</td>
<td>Standardised cognitive assessment is conducted by two years of age and repeated at transition to school.</td>
<td>Parents receive comprehensive and integrated care for their high-risk infant after discharge home.</td>
</tr>
<tr>
<td>Standardised hearing screening is conducted using Automated Auditory Brainstem Response (ABR) technology before one month of age, and where necessary diagnostic investigations are completed before three months and early interventions are started within the first six months.</td>
<td>Developmental progress and school readiness of infants born very preterm or with risk factors are assessed 6-12 months prior to initial entry into formal schooling, and education professionals receive training about the potential special educational needs of children born very preterm or with risk factors.</td>
<td>Mothers of infants born very preterm or pregnancy complications and their partners are counselled on the risk of recurrence in future pregnancies, and offered strategies to prevent recurrence, both before conception and during a subsequent pregnancy.</td>
<td>Standardised visual assessment is conducted by age 3.5 to 4 years and repeated by age 5 to 6, at which age additional attention is paid to visual information processing dysfunctions.</td>
</tr>
<tr>
<td>Key cardiometabolic risk factors (in particular blood pressure, abdominal obesity and physical inactivity) are monitored from childhood to adult life.</td>
<td>Targeted screening of parental mental health is undertaken six months after discharge and at two years, during regular follow-up visits for the child.</td>
<td></td>
<td>All very preterm infants and their families are offered preventive responsive parenting support after discharge home.</td>
</tr>
</tbody>
</table>

- Neurological status, motor development
- Behaviour, emotional and attention problems
- Comprehensive discharge management
- Communication, speech, and language development
- Peer and sibling relationships
- Respiratory health
- Cognitive assessment
- Comprehensive care after discharge
- Hearing screening
- School readiness
- Risk of recurrence
- Visual assessment
- Preventive responsive parenting support
- Cardiometabolic risk factors
- Parental mental health
TEG Patient safety & hygiene practice

- Hand hygiene
- Personal hygiene
- Environmental hygiene
- Central venous catheters
- Nurse staffing levels
- Safe use of equipment
- Care bundles for NEC
- Vascular access
- Patient safety and quality improvement
- Ventilator associated pneumonia
- Medication errors
- Multidrug-resistant bacteria
- Monitoring of physiological functions
TEG Data collection & documentation

Statements of the standards

- Quality information is available
- Indicators comply with published standards

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

Quality and health indicators in neonatal healthcare comply with published standards and help to increase comparability.
TEG Education & training of the multidisciplinary team working in neonatology

Statements of the standards

- All healthcare professionals develop and maintain competencies to provide safe and effective care through regular simulation-based learning.

- All healthcare professionals have access to and undertake continuing professional development to deliver safe and effective healthcare.

- Every healthcare professional caring for infants and their families delivers care based on the best available evidence, integrated with clinical expertise, available resources and the wishes of the family.

- All parents are provided with a training programme to facilitate their development as confident caregivers.

- Every healthcare professional is given access to and undertakes regular neonatal resuscitation training.

- Every healthcare professional has access to interprofessional education that enhances the delivery of practice in the care of infants and their families.

- Simulation training
- Continuing professional development
- Evidence-based care
- Competency based training for doctors and nurses
- Parents receive training programme
- Resuscitation training
- Interprofessional education
TEG Birth & transfer

Statements of the standards

- Transfer of mothers/infants
- Information and counselling about potential risk of preterm birth
- Organisation of perinatal care

Infants are transferred by a dedicated, specialised medical service that offers a quality of care similar to that promoted in a NICU.

Transfer of pregnant women for specialist care (for mother and/or newborn infant) is an essential component of perinatal care and is carried out in a timely, safe, and efficient manner.

All (pregnant) women receive timely information and counselling about potential risk factors for and signs and symptoms of preterm birth and how to find appropriate healthcare advice.

Pregnant women and their partners receive complete and accurate personalised information and support during pregnancy and childbirth to achieve efficient, optimal and respectful collaboration.

Perinatal care is organised in specialist and non-specialist centres to ensure access to optimal, preferably evidence-based, care with respect to medical knowledge, organisation structure, and staff.
TEG Medical care & clinical practice

**Statements of the standards**

- **Covers every main medical condition of preterm and ill babies (BPD, ROP, NEC, asphyxia, sepsis, jaundice, vitamin K prophylaxis, brain injuries...)**

<table>
<thead>
<tr>
<th>Measures are taken to identify, prevent, and manage hypoglycaemia in newborn infants who are at risk for impaired metabolic adaptation, including those with growth restriction, maternal diabetes, asphyxia, maternal beta-blocker medication.</th>
</tr>
</thead>
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<tr>
<td>Support of postnatal transition to extrauterine life is based on internationally consented guidelines, which are based on scientific evidence, and is performed in an appropriate structured and equipped environment by trained personnel.</td>
</tr>
<tr>
<td>Newborn infants at risk of Respiratory Distress Syndrome (RDS) receive appropriate perinatal care including place of delivery, antenatal corticosteroids, guidance around optimal strategies for delivery room stabilisation, and ongoing respiratory support.</td>
</tr>
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<td>Newborn infants with suspected early-onset infection receive prompt diagnosis and effective treatment of sepsis while avoiding overuse of antibiotics.</td>
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<td>Prophylactic supplementation with vitamin K for all infants is given to prevent vitamin K deficiency bleeding (VKDB).</td>
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<td>All newborn infants are assessed for neonatal jaundice with the aim of implementing effective prevention of severe hyperbilirubinaemia.</td>
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European Standards of Care for Newborn Health (ESCNH) project

1. Background – Why are standards needed?
2. The project – Why is it so unique?
3. The process – How were the standards developed?
4. Overview – The topics of the standards
5. Where to find the standards
6. Call to Action
7. What has been achieved so far?
8. Outlook
Where to find the standards

Overview

Infant- and family-centred developmental care (IFCDC) is a descriptive term for a framework of newborn care that incorporates the theories and concepts of neurodevelopment, neuro-behaviour, parent-infant interaction, parental involvement, breastfeeding promotion, environmental adaptation, and change of hospital systems. It is based on the leading-edge work of Als and her colleagues in the NIDCAP Federation International (NFI) (1,2) and Brazelton (3) and on the World Association for Infant Mental Health Declaration of Infants’ Rights. (4)

The core pillars of IFCDC are: sensitive care based on infant behavioural communication and cues gives the infant a voice (1,2) and is beneficial for brain growth (5), parent engagement supports parental wellbeing and infant development (6-10), and customised adaptations of the NICU environment and hospital system as a whole. (11)

The strategies for implementing this approach are based on supporting the unity of infant and parents, i.e. family access and integration into all care, early bonding, shared-decision-making, and parental involvement as the primary caregivers. (12,13) The practical implementation is assured by early and continuous skin-to-skin contact between mother or father and the newborn infant, as well as by the promotion and support of breastfeeding. (14) Sensory and environmental expectations of the newborn infant are paramount, since early sensory experiences have been shown to have significant impact on neurodevelopment. The model, therefore, advocates protection from deleterious environmental stimuli in newborn intensive care units (NICU) and access to positive sensory stimulation from parents and other caregivers. (15-18) Support strategies for families play a major role, including socioeconomic, mental health, and spiritual services as well as an individual case management plan for each newborn infant. This case management plan is established in collaboration with parents. (11) Well trained and supported healthcare professionals who receive counselling and regular clinical supervision in communicating with and providing emotional support for parents is the prerequisite for proficient successful implementation of IFCDC. (8,19,20)

The role of the Topic Expert Group on Infant- and family-centred developmental care focuses on defining practice standards for the implementation of newborn care that is centred around the infant and the infant’s family and their close supporters in order to support optimally the infant’s health and development.
Where to find the standards

Case management and transition to home
View more

Clinical consultation and supervision for healthcare professionals on supporting families
View more

Education and training for infant- and family-centred developmental care (IFCDC)
View more

Family access
View more

Family support services
View more

Management of the acoustic environment
View more

Parental involvement
View more

Support for parental-infant bonding
View more

Supportive sensory environment
View more
Where to find the standards

Family access
Infant & family-centred care

Authors

Target group
Infants, parents, and families

User group
Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard
Parents (and substitutes designated by the parents) have continuous access and are able to remain with the infant throughout the 24 hours.
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Call to Action for Newborn Health in Europe

Identify women at risk for preterm birth early and avoid transfers that result in increased morbidity and mortality and the separation of mother and baby by providing treatment in specialised perinatal centres where maternal and newborn care are located together.

Commit to evidence-based healthcare by providing modern health technology and an adequate number of staff. Easily comprehensible information for parents on treatment and care procedures needs to be available all times.

Provide sufficient specialist staff, particularly nurses and midwives, to ensure optimal care for babies.

Support parents of newborn babies in their role as primary caregivers from admission to hospital, promote infant- and family-centred developmental care and ensure parents 24-hour access to their baby.

Follow guidelines and recommendations on clinical environment and interior design to reduce stressful events for the vulnerable baby and provide facilities for parents and families that are sensitive to their needs and allow privacy with their baby.

Make adequate resources available to support optimal nutritional care that meets the baby's individual needs from the first day of life. Mother's own milk should always be the first choice and breastfeeding needs to be supported.

Promote shared decision-making between healthcare professionals and parents in ethically challenging situations. This includes providing psycho-social support for both, parents and healthcare professionals throughout the process.

Support coordinated, specialised, and effective follow-up and continuing care services for babies and children at risk for later developmental difficulties, as well as for their families. This provides targeted and evidence-based preventive measures to optimise child health and development as an important basis for the health and well-being of the whole family.

Ensure patient safety and adherence to hygiene practices by providing evidence-based information, equipment, and training for staff, parents, and visitors. This includes creating a blame-free error-reporting culture to improve healthcare quality and prevent adverse effects of care and treatment procedures.

Define and provide national and European-wide comparable datasets on pregnancy, birth, maternal, newborn, and child healthcare from conception into adulthood.

Ensure continuous education and training for all healthcare professionals working in maternal and newborn healthcare, including regularly updated curricula and training in sensitive communication and open interaction with parents.

Establish national frameworks for strategies to minimise risks before, during, and after birth.

Define indicators for long-term health and developmental outcomes and create quality measurement tools to allow benchmarking within and between hospitals and countries.

Support research into maternal and newborn health, develop and implement clinical guidelines and protocols to ensure evidence-based care, reduce mortality and morbidity, and improve quality of life.
Call to Action – How it can be used?
Call to Action – How it can be used?

Call to Action for Newborn Health in Europe

Define and provide national and European-wide comparable datasets on pregnancy, birth, maternal, newborn, and child healthcare from conception into adulthood.

Call to Action for Newborn Health in Europe

Identify women at risk for preterm birth early and avoid transfers that result in increased morbidity and mortality and the separation of mother and baby by providing treatment in specialised perinatal centres where maternal and newborn care are located together.

www.efoni.org
www.newborn-health-standards.org
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What has been achieved so far?

Development of 96 standards together with 220 experts from more than 30 countries

Support of 108 international and national healthcare professional societies
What has been achieved so far?

Support of 50 parent organisations
What has been achieved so far?

Target group and media-effective launch of the standards in Brussels – November 2018

- Bavarian representation in Brussels
- Evening event
- European Parliament
- Afternoon session
What has been achieved so far?

Publications and awards

- Infant journal “Combining forces for preterm infants” (2016)
- Awarded “Land of ideas” (2017)
- Several national publications
What has been achieved so far?

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Publications and awards

• Infant journal “Combining forces for preterm infants” (2016)

• Editorial in THE LANCET “The unfinished agenda of preterm birth” (2016)

• Awarded “Land of ideas” (2017)

• Editorial in THE LANCET Child & Adolescent Health (2019)

• Several national publications
What has been achieved so far?

Publications and awards

- Infant journal “Combining forces for preterm infants” (2016)
- Awarded “Land of ideas” (2017)
- Several national publications
Project communication strategy – educate, motivate, inspire

Main objectives

Information
All parties involved need to be exhaustively informed about objectives and strategies, the current working progress, results, decisions, and developments.

Coordination
Focusing and canalising all activities on the one common goal, developing, launching, and endorsing the standards project, is key.

Motivation
Whilst reservations are reduced, communication strategies shall enforce commitment, loyalty, and identification with the project leading to action in the individual countries.

Healthcare professionals, parent and patient organisations, affected parents, interested public, media, third parties (like NGOs and expert societies), politicians, payers as well as other relevant stakeholders in industry, science, and society
Features of the project communications

- Project homepage
- Social media
- Project report
- Presentation of the project at numerous events and congresses
- Print materials
- Image video
- Communication tools
- Promotion of the project by our partners
- Awards and acknowledgements
- Newsletter
- Political events

[Diagram showing various communication tools and elements related to the project]

Germany Land of Ideas
ASHOKA
Landmark 2017
Campaigning: Communication motto 11 months – 11 topics
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What will come next?

Decision on standard topics by Chair Committee

Development of template for the standards by Chair Committee

First standard draft written by one or more responsible authors as members of the TEG

Proof of content by the TEG’s Chair team

Peer review process: At least one feedback loop with the TEG members and EFCN

In case additional user perspective is needed: involvement of the Parents’ Knowledge Forum and external experts

Editing process regarding grammar and common wording together with Chair teams

Review by the authors

Final formatting

Voting on the standards by the Chair Committee; 80% yes votes needed

80%

Revision of the standards after a certain life cycle and extension of the standard topics

Now it’s time to act!

Support of the standards by healthcare societies, parent/patient organisations, and related Third Parties

Life Cycle

Implementation
From theory… to practice

Project

Development of European “reference“ standards

Need translation before they can be implemented on the national level

Implementation of standards needs to be on the national level

- Set up of the health system
- Specific country situation
- Level of detail in standard
- National requirements for standards

„Health is a country issue in the European Union.“
Outlook and implementation strategy

- More publications are to come
- Review and extension of existing standards (Life cycle)
- Development of measurement tools for outcome measures together with ICHOM in collaboration with Ludwig-Maximilians-University Munich
- Implementation research: what impact will the standards implementation have?
- Development of a self assessment
- Toolkit: Launch at jENS congress in Maastricht
- EFCNI Academy: Education modules in cooperation with professional societies and universities (pilot: „How to build up a human milk bank?“)
- EFCNI Fellowship programme: education modules for parent representatives
Training of parent representatives

2016
Level I workshop:
- Why are standards in neonatology needed?
- Differentiation between standards, guidelines, recommendations, and other definitions
- Requirements, strategies, and tools: how to drive country specific improvements for neonatal health
- Challenges in the implementation of the standards and how to handle them

2017
Level II workshop:
- Sharing best practice examples on activities to implement standards
- How to efficiently collaborate with others involved in neonatology
- Country specific implementation of the standards
- Project management strategies, 5 years plan for the promotion, and support of the implementation of the standards

2018
Level III workshop:
- Providing in-depth knowledge about the standard topics
- Call to Action – what is it and how can it be applied?
- Efficient stakeholder mapping and how to collaborate with healthcare professionals to proceed with standards implementation
- Project management

2019 and beyond
Level IV workshop:
- Sharing best practice examples on activities to implement standards
- How to use the toolkit for promoting and supporting the implementation of the standards

European wide implementation of the standards
Roadshow: presentation of the standards at single hospitals in the country (eventually all hospitals will have heard of the standards)
Outlook and implementation strategy

Conference in which all 11 topics were covered → working groups; standards are now looked into in detail
Outlook and implementation strategy

Roundtable with UNICEF, the ministry of health, and other stakeholders with the aim of prioritisation of topics in Ukraine
Outlook and implementation strategy

Roundtable with the ministry of health, and medical professionals prioritisation of topics in Bulgaria with follow-up project going on
Join us and support the implementation of the standards!

Experts from Belgium France and Switzerland already involved in the project:

- Dr Mirjam Schuler Barazzoni
- Livia Nagy Bonnard
- Charlotte Bouvard
- Prof Hans-Ulrich Bucher
- Prof Gérard Bréart
- Dr Laurence Caeymaex
- Dr Charlotte Casper
- Prof Daniele De Luca
- Dr Cecile Dubois
- Delphine Druart
- Dr Eric Giannoni
- Prof Pierre Gressens
- Prof Dominique Haumont
- Prof Petra Hüppi
- Dr Gilles Jourdain
- Dr Kai König
- Prof Pierre Kuhn
- Prof Alexandre Lapillonne
- Dr Ulrik Lausten-Thomsen
- Dr Nolwenn Le Saché
- Prof Delphine Mitanchez
- Prof Els Ortibus
- Dr Veronique Pierrat
- Prof Matthias Roth-Kleiner
- Prof Elie Saliba
- Dr Martin Stocker
- Professor Umberto Simeoni
- Prof Jacques Sizun
- Prof Pierre Tissières
- Dr Inge Tency
- Yannic Verhaest
- Prof Luc Zimmermann
- Dr Jennifer Zeitlin

https://newborn-health-standards.org/
standards@efcni.org
Supporting industry partners

Dräger was a project partner from 2013 to 2015
Shire was a project partner from 2014 to 2018

Their role: Participants at the Chair Committee meetings as silent observers, without voting rights, and no product related information sharing.

We thank our industry partners for supporting the project.
Open questions?

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Thank you very much for your attention!
Thank you very much for your attention!
European Foundation for the Care of Newborn Infants (EFCNI)

Chairwoman of the Executive Board: Silke Mader

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