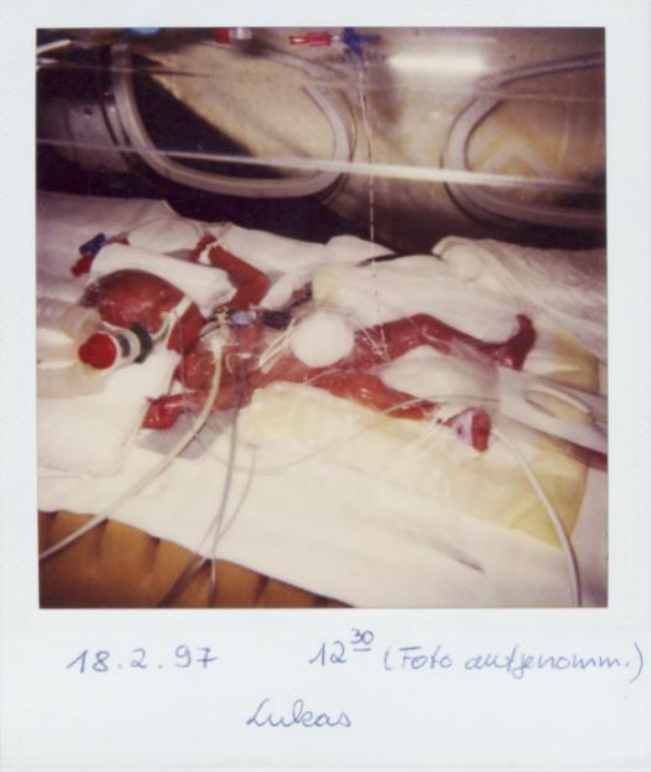
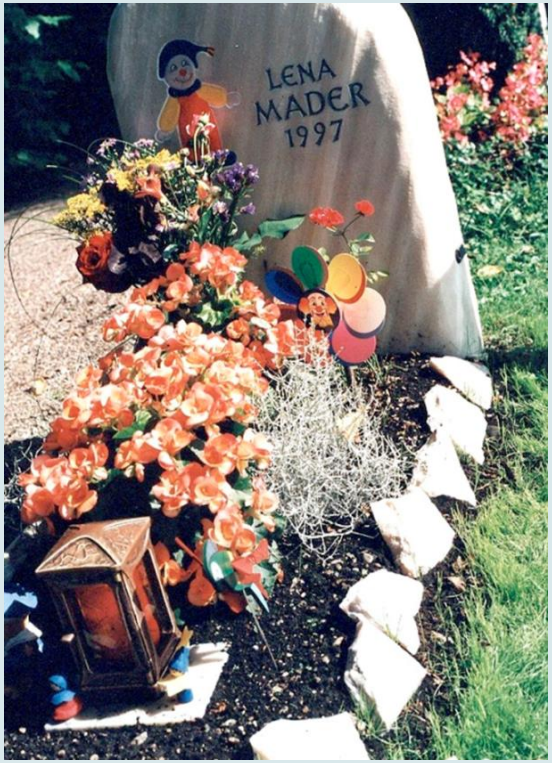
european standards of
care for newborn health

EFCNI

Newborn health standards – improving quality of care across Europe

That is not what we expected!!!





No support and just a few information for us parents

european standards of
care for newborn health

EFCNI

Why European Standards of Care for Newborn Health – is there a need?

Why European Standards of Care for Newborn Health?

Every year 700.000 preterm babies are born in Europe

8.7% of all live birth (6.3 % to 13.3 %)

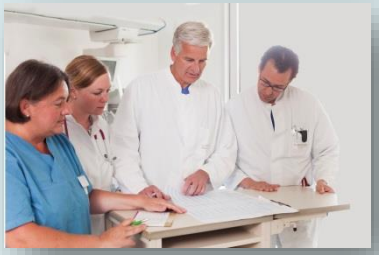
Lancet Glob Health 2018
Published Online
October 29, 2018

Differences between European countries

Infrastructure for high-risk pregnancies

Organisation of medical centres

Transport systems



Education of healthcare professionals

Follow-up and continuing care

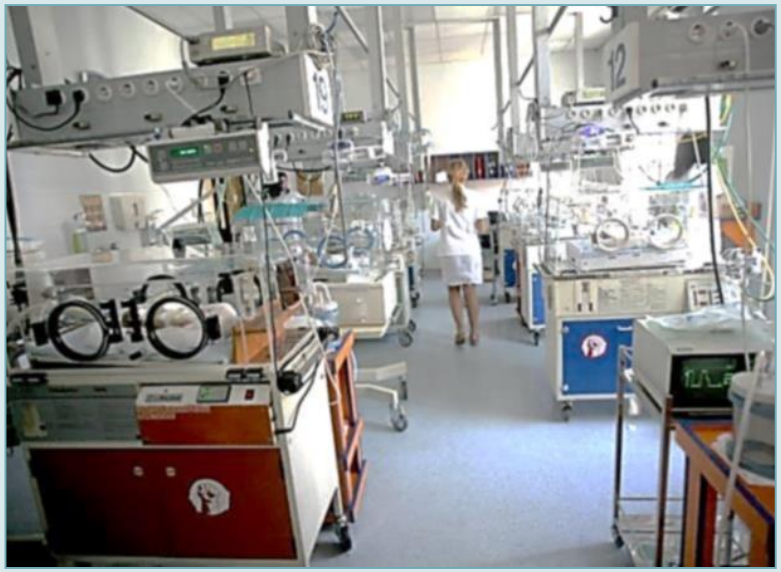
Medical treatment

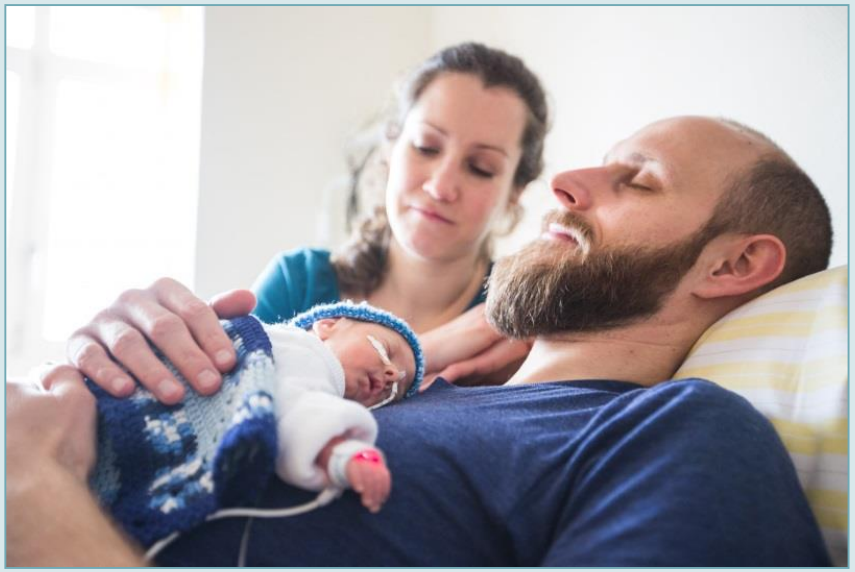
Level of implementation of infant- and family-centred care

Nutrition

NICU design

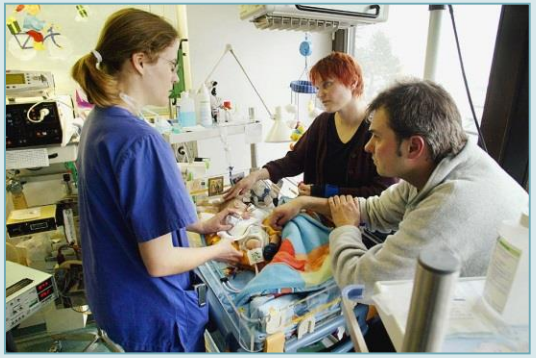
Inequalities in care and parent involvement among European countries

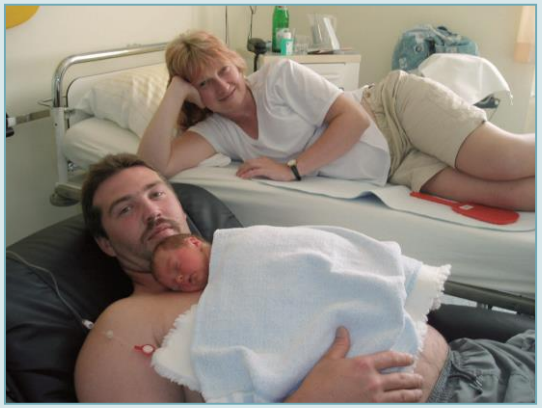




Coping with the situation depends on many things

- Experiences during pregnancy
- Experiences during the NICU stay
- Experiences with follow-up





Outcome and long-term consequences of preterm birth

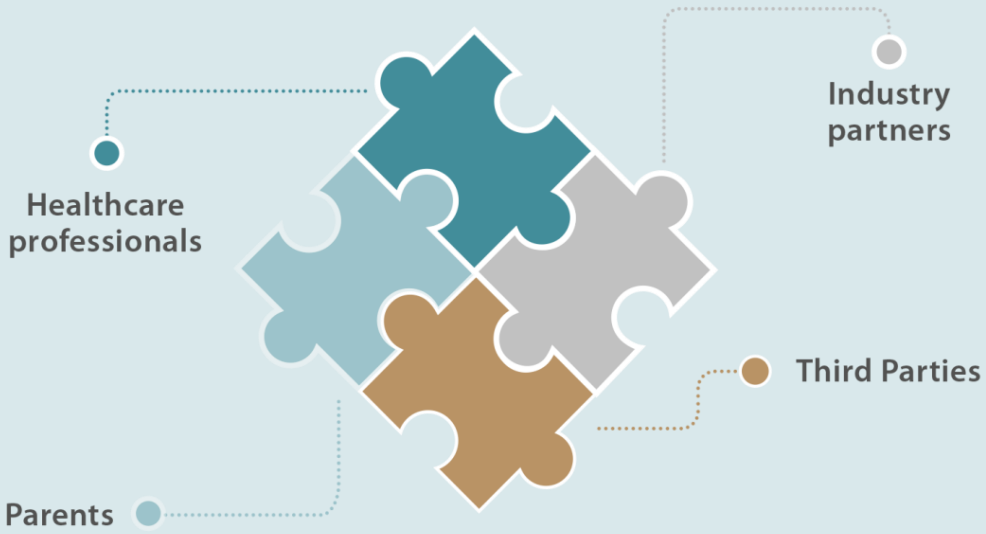
- Physical disabilities, e.g. cerebral palsy
- Learning disabilities
- Behaviour problems
- Psychiatric disorders
- Respiratory diseases
- Cardiovascular diseases
- Visual diseases

- Reduced educational attainment
- Reduced earning potential
- Reduced social integration
- Poor adult health

Working together

All stakeholders

- support the development
- actively participate in development process
- endorse the final standards



Kick-off and starting point

- Official start on 7 April 2014 in EU Parliament in Brussels
- Socks for life art exhibition
- Symbolic signing of request for the development of European reference standards by all present stakeholders and visitors of the exhibition

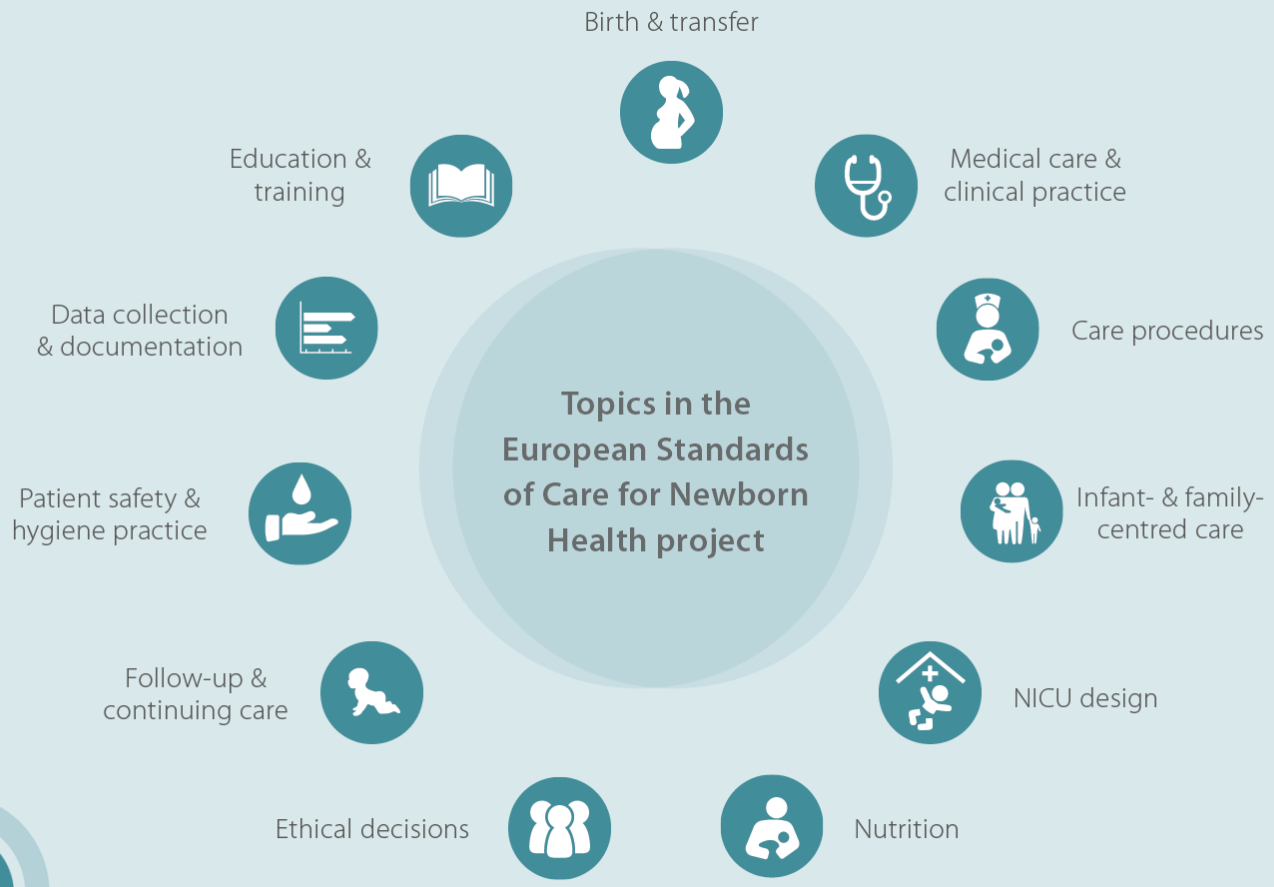
Why is this project so unique?

- Initiated by patient (parent) representatives for patients
- Parents are involved in every step of the development process

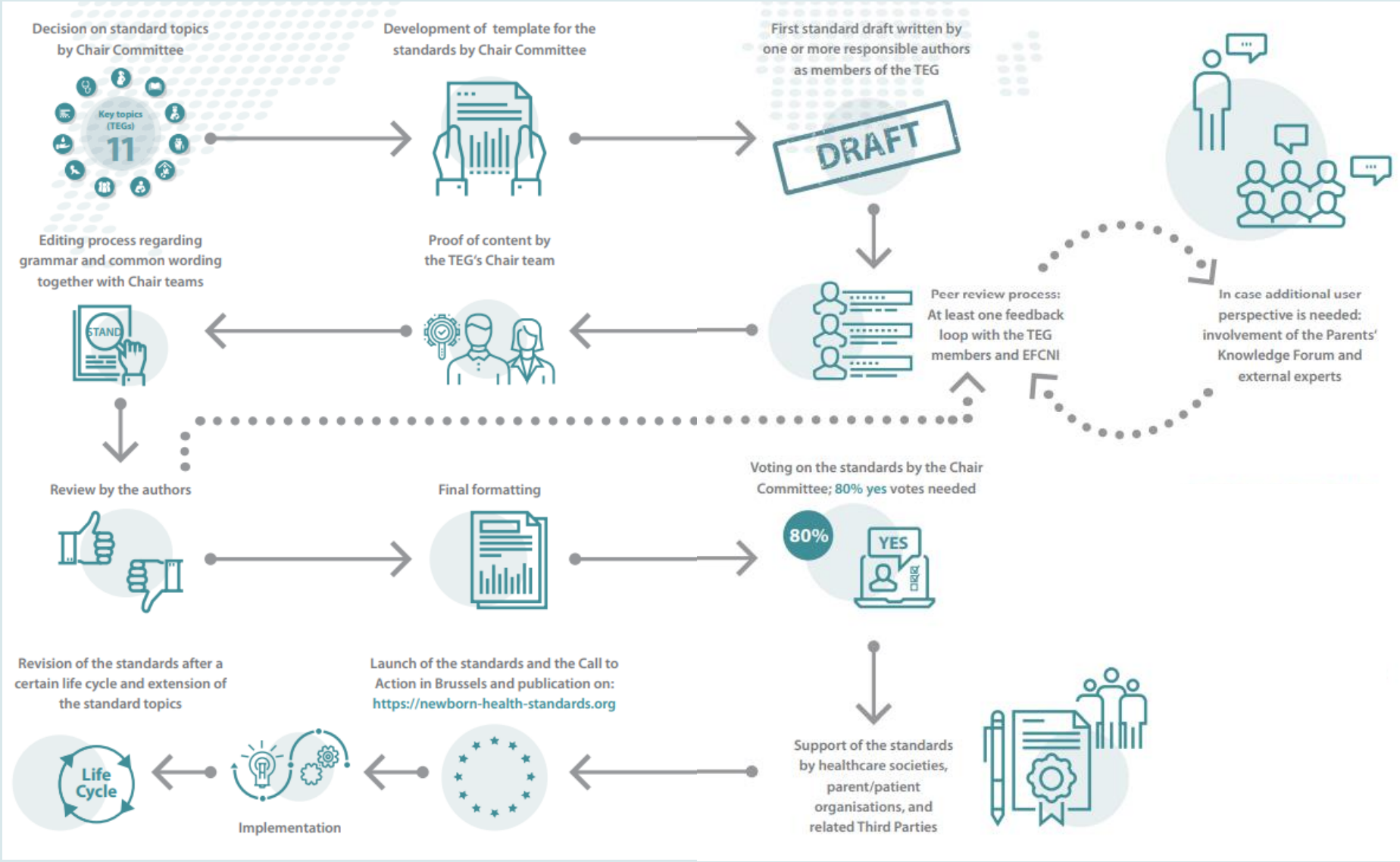
→ A true patient centred project

- About 220 experts from more than 30 countries developed the standards
- Combining forces across countries, disciplines and needs
- Supported by 158 professional healthcare societies and parent/patient organisations
- Covers the complexity of neonatal care
- Promotes the equitable and high levels of care

11 topic expert groups with 220 experts from over 30 countries



Standard development process



Targeted communication strategy

Publications and awards

- Infant journal “Combining forces for preterm infants” (2016)
- Editorial in THE LANCET “The unfinished agenda of preterm birth” (2016)
- Awarded as Ashoka Fellow (2015) and German Landmark Award (2017)
- Editorial in THE LANCET Child & Adolescent Health (2018)

Volume 12/Issue 6,

Combining
Foundatior

Iris Nikola Knierim,

The European Foun
European organisat
families. It gathers
and other stakehol
and newborn childr
possible prevention
in life. EFCNI's lates
supported by over
milestone for ensur

The unfinished age

For several years, World Prematurity
highlighted the global efforts to add
Initiated by the European Foundati
Newborn Infants (EFCNI), and later
organisation LittleBigSouls, the US or
Dimes, and the Australian National Pr
there are now many initiatives glob
shine a spotlight on the plight of
their families. An estimated 15 mill
before 37 weeks' gestation worldwi
is increasing, with rates varying fr
births between countries. In its lates
released on Nov 1, March of Dimes
C grade as the rate of preterm birt
the first time in 8 years from 9·57%
more worryingly, there were widenii
inequalities with the rate being 4
women and 15% higher among A
Alaska Native women than in white w
Preventing preterm births and
infants well to avert mortality and
morbidity is now one of the most u
further progress in delivering the Susta
Goal target of reducing mortality
than 5 years. In 2015, neonatal diso
2·6 million) of under-5 deaths, acc
Global Burden of Disease data. De
birth complications became the lead
mortality in 2015. Complicating aspe
the risk factors for preterm birth, su
diabetes, and other non-communicab
to air pollution, advanced maternal ag
nutrition are increasing not only in hi
but especially in low-income and midd
And some of the greatest health
between but also within countries ar
care, access to contraception and fa
birth attendance, and post-natal
women and girls are at particular risk
for many reasons, ranging from unfa
undernutrition to hard labour during p
Prevention has to take a lifecou
preventing teenage pregnancies,
and wellbeing of all women of child
pregnancies, improved pregnancy

www.thelancet.com Vol 388 November 12, 2016

Editorial

Putting the family at the centre of newborn health

The arrival of a newborn is a highly anticipated occasion. But for families with preterm and ill babies, the associated health challenges and psychological burden can make the occasion a stressful one. Each year in Europe, an estimated 500 000 babies—roughly 10% of all livebirths—are born before 37 weeks of gestation. Although much progress has been made to improve survival and outcomes in the past 40 years, premature birth remains a major cause of under-5 mortality and lifelong morbidities. Regrettably, the highly variable quality of maternal and infant care in Europe means that vast outcome disparities exist both between and within countries.

Published on Nov 28, the European Standards of Care for Newborn Health aim to define and harmonise “the care and treatment that shall be provided by a neonatal service”. Recognising that improving newborn health is a truly collaborative effort, the project was conceptualised and coordinated by the parent organisation European Foundation for the Care of Newborn Infants, which brought together around 220 experts across disciplines from 31 countries to work with parent representatives. The resulting standards cover 11 key topics—starting from antenatal and perinatal care, to transition to home, ethical decision making, palliative care, and long-term follow-up.

At the heart of the standards is infant-and-family-centred developmental care. While detailed clinical guidance is given on relevant issues such as preventing bronchopulmonary dysplasia and early-onset neonatal sepsis, a large proportion is devoted to empowering parents in taking up their roles as primary caregivers. When given individualised support, parents' participation in daily care procedures in the neonatal intensive care unit (NICU) such as nappy changes, bathing, and weighing can reduce stress, increase care-giving competency, and strengthen parent–child bonding. The standards also advocate 24 h access for parents to the NICU and recommend provision of a supportive sensory environment that minimises exposure to excessive light, noise, and other stressful stimuli. Where painful medical procedures are necessary, parents are encouraged to recognise their baby's discomfort signals and to provide non-analgesic pain relief—for example, by breastfeeding and having skin-to-skin contact with the infant.

To ensure continuity of care after hospital discharge, the standards recommend providing families with a comprehensive plan that includes tailored education, training, and ongoing psychosocial support for parents. Assessment of the infant's neurological status, cognitive, motor, and language development, as well as respiratory, cardiometabolic, and other health outcomes should be included in continuing care. Such long-term follow-up is essential to enable early identification of any concerns and rapid intervention, so that these children can continue to thrive at school age and beyond.

Although these recommendations are already part of routine practice in some countries, the establishment of a harmonised set of standards represents an important step towards equitable outcomes for premature and ill infants across Europe. Each standard is broken down into components for parents and families, health-care professionals, neonatal units, hospitals, and health services—exemplifying the concept that close collaboration at all levels of the health system is essential. Evidence-based clinical practice needs to be implemented with the infant and their family in mind, respecting that each family has different needs and requires individualised support to achieve the best outcome for their child.

Importantly, although some recommendations require substantial investments, initial steps are proposed so that immediate actions can be taken. Some simple steps include putting up a folding screen to guarantee privacy, carefully explaining medical conditions and management plans to parents, and providing information about available professional and peer-to-peer support services.

We call on national health systems to review their protocols in light of these standards, identify priority areas for change, and establish strategies for implementation. To monitor progress and enhance accountability, clear indicators for meeting the standards have been proposed, although challenges remain in the systematic collection of data that can be compared across countries.

Decades of research have refined our knowledge of neonatal health and improved survival of preterm and ill infants. It is now time to translate the evidence into the best quality of care for patients and their families, no matter where they live. And it all starts with respecting the rights and dignity of the infant and their family, and recognising these early weeks as a pivotal stage in the pathway from fetal life to adulthood.

■ *The Lancet Child & Adolescent Health*

www.thelancet.com/child-adolescent Published online November 27, 2018 http://dx.doi.org/10.1016/S2352-4642(18)30369-9 1

Germany
Land of Ideas
Landmark 2017
Nationaler Förderer
Deutsche Bank

Support of 108 healthcare societies and organisations

Support of 50 parent organisations and 7 industy partners

Dräger supported the project from 2013 till 2015

Launch in the EU Parlament in Brussels

- Reception in the Bavarian Representation

- Conference in the European Parliament

Outlook and implementation strategy

european standards of
care for newborn health

EFCNI

Some personal thoughts…

Going home after four month in the hospital

Our life does not stop after discharge

We have learned to life with our destiny

Take home message:
Now we need to act - this Mission is Possible!

- Support the implementation of the standards in your country
- Support newborn health on national level
- Join forces on national and international level to improve newborn health
- Work together with your national and if existing local parent organisations
- Join us in and support for the Call to Action for Newborn Health in Norway and in Europe

https://newborn-health-standards.org/